

What we did this year.



Our mission.

Epilepsy Scotland works with people living with epilepsy to ensure that their voice is heard.

Our vision.

We believe that people living with epilepsy have a right to:

- be free from stigma and discrimination
- have access to high quality medical, social, educational, support and information services
- be valued and included in society
- determine their own way of life

Our work.

- we fight discrimination and stigma experienced by people with epilepsy
- we influence public policy to achieve best practice for people living with epilepsy
- we work to ensure that appropriate services and support are available
- we sustain an effective, supportive and financially secure organisation

People of all ages can develop epilepsy regardless of gender, ethnic background, sexuality, ability or social group. Epilepsy affects one in 130 people in Scotland. It is the most common serious neurological condition in the world.

A message from our Chief Executive.



Lesslie Young,
Chief Executive.

Strength of purpose and commitment is tested not by what you do when times are easy but your actions in the hardest of times.

In the most difficult economic climate for a generation or more I have chosen to take a positive attitude to the pressures and challenges we face. I choose to see it as a time of opportunity. It is a time to focus the mind and the purse strings and a time to think innovatively and create a new way forward. As Chief Executive it is incumbent on me to ensure the wellbeing of Epilepsy Scotland, those it employs and those it represents. This is a delicate balance to achieve.

Epilepsy Scotland has been more active than ever before over the last year. I am particularly pleased to highlight the progress we have made in partnership with the Scottish Justice System. Training to probationer police officers is being provided at The Scottish Police College as is training for Procurators Fiscal. We are in the process of developing training for The Law Society and we have recently met with the Justice Minister, Mr Kenny MacAskill who is supportive of our plans and has committed to helping in any way possible.

We have moved into our new premises in Edinburgh. Our Choices service there continues to improve as evidenced by their inspection report where every grade has increased from last year. In addition Michael Adair our Social Worker and Zoe Reid our Youth Worker have won an award from the Marsh Trust via Barnardo's and will travel to London to receive their outstanding achievement in work with "Children & Families".

We need to plan and prepare for the upturn so we hit the ground running. We are developing new services and planning the expansion of existing ones so that as soon as is possible we can improve our acknowledged high quality support for the 40,000 people living with epilepsy in Scotland. We cannot allow ourselves to tread water.

With that in mind we have established a Community Interest Company (CIC) to start to generate income to fund our plans. Whilst never significantly threatened we thought it prudent not to wait for others to decide our fate but to take our future into our own hands. Our wholly owned subsidiary, Charity Clear will not yield a fortune overnight. It needs time to grow. As a social enterprise it represents a benchmark of how the third sector can successfully work with a commercial mindset.

This does not mean we no longer need your support. We need it now more than ever. You continue to be central to all that we plan, develop and do. The level of our success is dependent on our Fundraising, Policy and Communications experts who keep us appraised of what is happening in an ever changing and challenging public forum.

I said at the beginning that purpose and commitment can be measured by the actions taken in difficult times. I, like everyone else in Epilepsy Scotland, am committed to ensuring support for those living with epilepsy is of a consistently high standard and is readily available for years to come. I feel confident the actions I have taken on behalf of the organisation will achieve that.

Our work is essential and is in greater demand. We need to be flexible and bold to meet the demand. Your support will enable us to continue to do so.

Here's to the challenges of the future and the opportunities they bring with them.

Lesslie Young

INTRODUCTION

A message from the Chairperson.



Helen Carmichael.

It is with a great deal of pride that I write this, my second annual comments as Chairperson. The reason I say this is because despite the ongoing economic crisis, Epilepsy Scotland continues to be an effective and growing voice for those affected by epilepsy. The efforts and dedication of all of the staff in the organisation have borne real results as our Chief Executive's comments bear testament to.

This is no mean feat - our organisation like so many other charitable causes is feeling the tangible results of the downturn. Despite this by facing the challenge, with the vision and guidance of our Chief Executive supported by committed and talented staff members, I am confident that we can weather the storm and look to an even brighter future.

Helen Carmichael

INTRODUCTION

A message from our Patron.



Baroness Linklater of Butterstone.

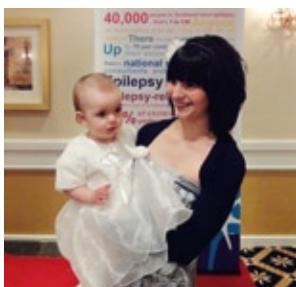
I am delighted to have been invited to be the patron for Epilepsy Scotland. It is an organisation which is doing outstanding work on behalf of countless people the length and breadth of the country who are involved with epilepsy in some way. Whether they have epilepsy, are the families of those with epilepsy or others who in so many ways work so hard and effectively in the field, I have been deeply impressed by the quality and scope of the work that Epilepsy Scotland undertakes on their behalf.

Its bold and creative plans also bode well for the future. I will do my best to support and encourage everyone associated with Epilepsy Scotland and do what I can to promote its achievements.

Baroness Linklater of Butterstone

Epilepsy Scotland strives for a better deal for people with epilepsy.

We have been working hard on a number of issues this past twelve months, to make life better, fairer and safer for people with epilepsy, their families and carers. We look forward to developing these further in the coming year.



crews can best help those having seizures in the community.

We are working with MSPs to protect the role of Epilepsy Specialist Nurses in the NHS and to highlight the vital contribution they make to the care of people with epilepsy.

We began working towards better planning for people transitioning from child to adult and from adult to later life services. We want to make sure both young and older people with epilepsy are properly supported as they move through health, education and social services.

We have partnered with the Scottish Ambulance Service to create better pathways for people with epilepsy who need emergency care. Together, we are looking

at how ambulance

We helped to form a set of clinical standards for neurological services, to help ensure people all over the country get equal access to good quality epilepsy care, wherever and whenever they need it. We are currently working with the NHS to implement these.

We requested a review of how cases involving epilepsy come to court. Some people with epilepsy commit minor crimes during or shortly following a seizure, whilst they are unaware of their actions. Often these cases take a long time to come to court and most are dismissed. Epilepsy Scotland is pressing for a fairer system that will save unnecessary distress for people with epilepsy and their families. Also, new police recruits now receive epilepsy first aid and awareness training thanks to the efforts of Epilepsy Scotland.

Cabbie Jamie Simpson keeps his epilepsy first aid card handy.

This handy little card is just one of the ways that Epilepsy Scotland works to increase the public's understanding of epilepsy. The card was launched this year by Rosie Gilmour our new Ambassador.

CAMPAIGNING

Promoting change.



Epilepsy Scotland's focus remains the same as when it was founded 55 years ago. We believe increasing people's understanding of epilepsy and informing public attitudes helps

banish social stigma and discrimination. Here are just some of the ways in which we've achieved this over the last 12 months.

Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon warmly congratulated Epilepsy Scotland for its work and services back in December 2009. She was the guest speaker at our 55th celebration in the Scottish Parliament.

Baroness Veronica Linklater became our new Patron. Months later we invited Dunblane teenage model Rosie Gilmour to be an Ambassador for Epilepsy Scotland. Both women took part in our National Epilepsy Week reception and book launch in the Scottish Parliament. The theme was epilepsy and the under 25s. Rosie Gilmour was one of three young women sharing how epilepsy impacted their life.

The Scottish Parliament Cross-Party Group on Epilepsy grew once again this year and is supported by 32 member MSPs. We administer the Group on behalf of the Joint Epilepsy Council of the UK and Ireland (JEC). Members have looked at epilepsy and mental health and wellbeing, occupational health, schools awareness training and transition services. They challenged delays in social work Section 23 assessments. They also questioned legal processes for dealing with minor crimes committed by people with epilepsy while they are in seizure activity and unaware of their actions.



The UK Government announced proposals to allow pharmacists to dispense generic (cheaper, non-branded) medication in 2010. We and the JEC objected. Epilepsy Scotland then led a Scottish campaign for continuity of supply, endorsed by many MSPs and people with epilepsy. We met with the Chief Pharmacist who acknowledged our concerns. These will be raised when a Scottish consultation on generic substitution takes place.

Fiona Duffy won our 11th Journalist of the Year award for her Daily Mirror article about missed diagnosis and inadequate epilepsy services. Judges were impressed by the very high standard among the largest number of entries to date. Panellists included our Patron Baroness Veronica Linklater, TV and radio broadcaster Cathy MacDonald, Scottish NUJ Secretary Paul Holleran and BBC Scotland's Head of News and Current Affairs, Atholl Duncan.

We continued to draw national media coverage for epilepsy stories. Local papers loved the Braille helpline card promoted by Big Brother runner-up and RNIB Insight Radio presenter Mikey Hughes. Thanks to Barbara Mackenzie at Cullin FM, thousands of Scottish households heard our National Epilepsy Week community radio advert with a free backing track by Paulo Nutini.

"The Scottish Parliament Cross-Party Group on Epilepsy grew once again this year and is supported by 32 member MSPs."

Mary Macfarlane realised she wasn't alone when we came to Wester Ross.

Our information events are a valuable resource for people to access information and meet staff face to face. They raise awareness for the condition and have proven to be popular! We make sure we cover the whole of Scotland.

EVENTS

Information and support.



"I found the event very helpful, as a student nurse we do not really learn too much about epilepsy and it's good to know that there are available resources to contact if in need of

relevant and current information."

Support groups form a network

Epilepsy support groups from across Scotland were invited to come along and join in the first ever National network for support groups. The event was held in Dundee. Epilepsy Link Officer Craig Blair commented *"this was a fantastic opportunity for people to come together for the first time to share ideas, concerns and meet other people with epilepsy."*

The network discussed key issues and shared ideas. There were excellent examples of how support groups can make a huge difference in their local communities. The network allows groups to support each other and encourage ideas benefitting all involved. Due to the success, we hope this will become an annual event which will grow from strength to strength! We hope that more groups will join the network to help support one another and build on this years success.

"Really helpful, I feel part of other areas now, sharing stories and inspiring ideas."

If you would like to get involved with a support group or feel you have a group that should join the network please get in touch. You can also find out more about your local support group. Contact Craig Blair, Epilepsy Link officer on **0141 427 4911**.



"It has been a great day. Good to hear from other groups about a whole range of issues. I look forward to meeting up with other groups. From this meeting I will be able to go back to Dumfries and Galloway with a lot of information that will help our group."

New ways of getting in touch

During the last year we have expanded our social networking sites. More and more people are using social networking to communicate. This allows people to keep in touch with us and find out the latest news. We currently have more than 700 people and organisations across the world that choose to follow and support our work on Twitter. Our fan base on Facebook has also increased which is really positive and more than 800 people have become a friend of Epilepsy Scotland. This is extremely encouraging. Find us on Facebook and Twitter.

Service user forum underway

Preparations are under way to form a new forum for Epilepsy Scotland Service users. All service users from the Community Outreach Service, Choices service and the Lighthouse Youth Project in Edinburgh were invited to the first event in 2010.

Sima Rezayan had never spoken to anyone about epilepsy before.

Our helpline is always busy taking calls from people looking for some information or simply needing to talk.

IN TOUCH

Continuing success with helpline.



All of our helpline staff has a COSCA Certificate in counselling skills, making our service stand out. We continue to provide a professional and empathic service to anyone who calls

us. Telephone enquiries range from people who have just been diagnosed and want to learn more about epilepsy to those coping with difficulties in employment. We also receive a high volume of calls from parents needing support to cope with their children's epilepsy. Professionals call us too – from GPs to employers, teachers and Occupational Health Doctors. We can provide information, or just listen – we're happy to support in any way we can.

Over the last 12 months our helpline has received over 2000 calls. Many of these calls are lengthy and complex, covering many issues and almost 450 came from professionals. As would be expected nearly 1500 of the enquiries were by phone, with almost 300 by email and approximately 30 SMS text messages. The majority of our calls still come from the Greater Glasgow and Clyde area followed by Lothian. This year, we have noticed an increase in calls from other UK countries as well as several international enquiries.

"Epilepsy Scotland - my saviours when I got diagnosed."
Helpline caller.

"The lady I spoke to was very helpful and friendly and gave me much more help and information than any specialist or GP. She was a friendly voice and advised to call anytime."
Helpline caller.

Finlay Clarke (5) thinks our booklets for children are “yeah, really cool”.

Earlier this year, we launched two booklets for children of pre-school/early primary school age, explaining epilepsy. Finlay is a fan.

IN TOUCH

Our new publications.



For the children's booklets, we worked with a children's illustrator and the resulting books were launched at the Scottish Parliament during National Epilepsy Week.

The first book tells the story of Brian who finds out that his mum has epilepsy and learns what to do if she has a seizure. This has been very well received by parents with epilepsy who need to find a way to explain their condition to their children. The second book introduces Farah, a young girl who is going through the process of being diagnosed with epilepsy. Epilepsy Specialist Nurse colleagues have told us that it is very helpful to prepare the children for the tests that are carried out in the hospital.

New look publications

We are giving our publications a makeover! Earlier this year we unveiled our new logo. As we review, update and reprint our publications they will undergo a re-style at the same time. Look out for our new leaflets over the coming year.

You can trust our publications. All are extensively checked by medical professionals to ensure medical accuracy. In addition, we also involve people with epilepsy at the early stages of writing the guides.

In order to respond quickly to demand for specific information, we have started our own in-house range of short, fact-based information sheets which supplement our more comprehensive printed guides. Check our website for new factsheets.

That's not all. We are currently working on two more publications for children and a guide for teenagers. We aim to ensure everyone in Scotland has the information they need when they need it.

Ben Hastie will beat his own time next year at the Great North Run.

Our brave volunteers and supporters helped to raise £16,453.14 for Epilepsy Scotland through a variety of exhilarating events throughout the year including zip slides, abseils, marathons and triathlons.

FUNDRAISING

Helping Epilepsy Scotland thrive.



Our fundraising team has done a great job this year! Here are just a few ways in which they have inspired people to raise enough money to help Epilepsy Scotland thrive:

Our loyal committed and payroll givers helped us to raise over £63,500 by donating every month by direct debit, standing order, or through the Give As You Earn scheme

We held our annual Wags dinners in both Glasgow and Edinburgh with four speakers at each competing to become the 'Wag of the Year'. We held our seventh Art Sale and Auction and welcomed some Glasgow Warriors rugby players to our second Ladies Lunch and Fashion Show. Each of these events, and the generosity of those who supported them, raised over £86,000

Our first Christmas Fair at the Trades Hall raised £479.40

Loyal supporters in the Perth area gave their time to support the Epilepsy Scotland Christmas card stand in the AK Bell Library and raised £1,221

We are one of the six member charities who make up Bighearted Scotland. We all work together to raise vital funds for our work in ways that we can't do as individual charities. Last year we raised £12,000 – through payroll giving and the awards dinner

We held our first sponsored freefall from the Titan Crane in on Clydebank.

A huge thanks to Christine Robertson of Inverness who trekked up Mount Kilimanjaro and raised over £8,500 for Epilepsy Scotland. Thanks to our daredevil zip sliders at Click Networks and Jen Mahaffy, and triathlete Mike Stark. Also thanks to Eileen Rae, Jacqueline Ferrier and the Comrie Toddler Group who have also raised vital funds for the work we do.

Isobel Whiteford found friends for life through our outreach service.

We not only support people to live to their full potential, but also give people the opportunity to meet people, make friends and create their very own support network.

LIFESTYLE

Support networks.



Choices

Choices is an Edinburgh-based service providing one to one support to people with epilepsy and additional support needs. This past year has been exciting

and busy, with the service constantly expanding, and a number of new staff have been taken onboard. We've seen successes for our services users in all sorts of ways – improvement in seizure control, college certificates gained, work placements achieved, and personal goals met. Some of our services users have ventured into the office to make use of new our equipment, and to see how things work 'behind the scenes'. Others are looking forward to the start of the service-user forum, which they plan to attend.

Community Outreach Service

The Community Outreach Service provides individualised support to adults in Glasgow with epilepsy and additional needs. Our support workers use a person-centered approach to help enable clients to live a fuller life. This year, they support service users with a wide range of activities, from creating employment and educational opportunities to living more independently and making decisions about the future. We received another excellent Care Commission report on the service, which praised the close involvement of service users in how it is run. Also highlighted were focus groups which were held to develop further activities, where many service users made new friends.

"The service and staff have been exemplary; I would not be able to do without their help."

Service user.

"I can't speak highly enough of them, they do an excellent job."

Service user.

Ellie Jones felt 'completely herself' during the residential trip.

The Lighthouse Youth Project enables young people to meet others and share their experiences. This helps to alleviate feelings of loneliness, confusion and isolation.

YOUNG PEOPLE

The Lighthouse Youth Project.

A diagnosis of epilepsy can be a frightening and confusing experience at any age. Teenagers are particularly sensitive about how their epilepsy will affect their education, emotions and social life.

The project works with young people in two age groups. The Youth Group (11-15) and the Transition Group (15-19). This allows us to provide tailored, age specific activities and support. For example the older group focus on issues like drugs, alcohol, relationships and higher education.

Zoe is our Young Person's Worker. Zoe attends an NHS seizure clinic supporting newly diagnosed young people. She is also currently developing a schools awareness programme to widen the understanding of epilepsy and to encourage other young people to join the Lighthouse Youth Project.

"I think it is a fantastic project for the kids and parents. The whole project is a lifeline to me and my family. Just speaking to the staff on the phone for advice and reassurance is great."

"I realised that I can reach goals that I never thought I could, for example, climbing up the 60ft tree. This increases my self-esteem as I can believe that I can achieve an activity I thought was impossible for me to do."

What we offer

- Individual and group support sessions to young people, their families and carers
- Fun social and physical activities
- After school and school holiday activities
- Help to produce CV's and applications for both work and further education
- Advocacy on behalf of the individual and their families
- Support and information in relation to benefits, housing, education and employment

If you would like more information about the Lighthouse Youth Project, please contact Michael Adair on **0131 226 5458**.

Sam Huston feels he can confidently manage a seizure at work.

This year has seen the reintroduction of joint working with NHS Education and the delivery of more specific epilepsy training for Primary Care staff.

LEARNING

Training achievements.



Epilepsy Scotland continues to provide training to suit the wide ranging needs of our customers. From the provision of awareness raising sessions giving people a basic understanding of what epilepsy is, through to the EPASS accredited management of epilepsy and the administration of rescue medication courses.

Over the past 12 months we have worked hard to influence the training provided to the front line staff of the Scottish Ambulance Service. By forming a working group for training development, we were able to ensure the Scottish Ambulance service had more of the information they need to deal with epilepsy emergencies effectively.

We have also influenced the training of new recruits at the Scottish Police College at Tulliallan. As part of their probationer training, new recruits are being taught about the range of seizure types and how people may present just before or just after a seizure. By being aware of these behaviours we hope that less people will be arrested wrongfully. We are currently in discussion about rolling this training out to operational officers also.

In the next year we hope to expand our training portfolio, with Epilepsy First Aid and more specialised training such as Epilepsy and Learning Disability.

Between July 2009 and June 2010 we delivered 192 courses to 2029 people.

A huge thank you to the following Trusts and Foundations.

Agilent Technologies
Agnes McCallum Bequest Fund
Alexander Moncur Trust
AM Pilkington Charitable Trust
Andrew Paton Charitable Trust
Ann Jane Green Foundation
Bellahouston Bequest Fund
Bink's Trust
Cecil Rosen Foundation
Christina Mary Hendrie Trust
Cruden Foundation
Cumberland Building Society
Charitable Foundation
Darroch Charitable Trust
Edinburgh Soveriegn Council Charitable Trust
Gannochy Trust
Hoover Foundation
Hugh Fraser Foundation
Incorporation of Maltmen
James Inglis Trust
James Wood Bequest Fund
JTH Charitable Trust
Kola'a Trust
Leatherseller's Company Charitable Fund
Leng Charitable Trust
Lloyds TSB Foundation for Scotland
Lynn Foundation
Margaret K Murdoch Charitable Trust
Martin Connel Charitable Trust
Mary Andrew Charitable Trust
MEB Charitable Trust
Merchants House of Glasgow
Miss I F Harvey's Charitable Trust
Mrs M A Black's Charitable Trust
Mugdock's Children's Trust
Northwood Charitable Trust
PF Charitable Trust
R J Larg Family Trust
R S Hayward Trust
R S Macdonald Charitable Trust
Rank Foundation
Roald Dahl Foundation
Robertson Trust
Robertston Charitable Trust
Ronald Miller Foundation
Row Fogo Charitable Trust
Russell Trust
Saints and Sinners Trust
Scottish Healthcare Charitable Trust
ShareGift, The Orr Mackintosh Foundation
Sir Iain Stewart Foundation
Souter Charitabe Trust
St Katharine's Fund
Strathclyde Police Benevolent Fund
Talteg Limited
Tay Charitable Trust
Trades House of Glasgow Commonweal Fund
William Grant and Sons

Our income and expenditure for the year ending March 2010.

Income	2009 (£)	2010 (£)
Donations, legacies and events	1,007,109	400,772
Grants, training and literature	680,804	722,538
Membership and other	55,318	29,367
Total	1,743,231	1,152,677

Expenditure	2009 (£)	2010 (£)
Implementing our vision	1,075,018	1,211,491
Costs against generating income	250,531	207,196
Governance	42,178	29,476
(Gain)/Loss on investment	18,929	(29,382)
Total	1,386,656	1,418,781

Funds	2009 (£)	2010 (£)
Restricted funds	153,152	129,235
Unrestricted funds	1,112,230	929,105
Total	1,265,382	1,058,340

The year April 2009 to March 2010 ended with a deficit of £266,104 after gains realised on investment.

Statement by the Independent Auditors

In our opinion the summarised accounts are consistent with the full annual accounts of the charity for the year ended 31 March 2009. Contact Epilepsy Scotland if you require a copy of the full accounts.

Carrie Jones joined us just last week, why don't you?

Perhaps you have been newly diagnosed, are living with epilepsy or caring for someone with the condition and want regular news and information? Maybe you are keen to add your voice to campaign and raise awareness on behalf of everybody in Scotland with epilepsy? Wherever you are on your journey with epilepsy, you can benefit from our member services and activities.

The more members we have, the more weight and influence we carry as an organisation. If you would like to join, please fill in the form insert and return it to the address below. We'd love to welcome you as a member today.

Freephone **0808 800 2200**

Epilepsy Scotland
FREEPOST SC02178
48 Govan Road
Glasgow
G51 1BR

By joining as a member of Epilepsy Scotland, you will:

- Receive a welcome pack and membership card
- Receive our biannual newsletter 'Epilepsy News', keeping you updated on medical advances and sharing the experiences of others with epilepsy
- Be able to contribute and influence decisions by voting at our annual general meeting (if you are over 16)
- Be entitled to epilepsy training at a special discount rate
- Be able to help us lobby for better care and services for people with epilepsy
- Hear about what we are doing on your behalf
- Be supporting Epilepsy Scotland's activities all over Scotland

Thank you for all the dedicated help and guidance.

Epilepsy Scotland appreciates the investment and dedication shown by the Board of Directors:

Mrs Helen Carmichael (Chairperson)
Mr Tom Russell
Dr Jean Barclay (Vice Chair)
Dr Susan Duncan (Vice Chair)
Miss Nellie Buchanan (Treasurer, resigned March 2010)
Dr Bill Scott
Mrs Chris Ritchie
Mr Brian Henson
Miss Alison Anderson
Mr Andy Ormes
Mr Ian Buchanan
Ms Susan Watt (resigned December 2009)
Chief Inspector Ross Bennet (resigned December 2009)
Dr Richard Roberts
Mrs Marilyn Bryce
Mr Gordon Quinn (appointed January 2010)
Professor Ian Bone (appointed January 2010)
Dr Robert Sharpe (appointed February 2010)
Dr Liam Dorris (appointed February 2010)

We would also like to thank all of the volunteers who have supported the work we have done over the past 12 months and who continue to support us everyday.

Epilepsy Scotland,
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Email: enquiries@epilepsyscotland.org.uk

Web: www.epilepsyscotland.org.uk

Twitter: twitter.com/epilepsy_scot

Also find us on Facebook!

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