Racing ahead for epilepsy

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The saying “times flies when you’re enjoying yourself” is certainly true.

Since the last newsletter, I have enjoyed meeting members and hearing how you feel we are representing and supporting people living with epilepsy.

I would also like to thank staff, other organisations, Epilepsy Specialist Nurses, doctors and members of the public for their valuable feedback.

Personal stories are so important and help people to understand the impact of living with epilepsy. We asked four people to share their experiences for a “Different Faces, Different Stories” short film. The first screening at our Wag of Wags dinners played a large part in these very successful events. Two stories went into our direct mailing campaign to raise funds for existing and new services.

Our information leaflets are now provided free of charge to all sectors. Every GP practice in Scotland received a full set so that accurate information is readily available.

We want to do the same for employment. We are working with Occupational Health professionals to produce a new guideline which should ease the difficulties experienced by some of you in the workplace.

Several new initiatives have started. We are planning a conference to make transition to health and care services easier and less confusing. A new logo is being designed to increase public awareness and market our services.

For the younger generation and the young at heart our Epilepsy Scotland blog will soon go live. You can follow my fundraising walk through the Great Glen Way in March next year.

There’s much to celebrate already and ahead is Epilepsy Scotland’s 55th birthday on 1st November. The vitality and initiative of those who founded this organisation continues today. We are committed to improving the lives of 40,000 people with epilepsy and Epilepsy Scotland will continue to grow and evolve to meet the demands of those we represent – you.

The difficult times we live in means we greatly value your continued generosity. Thank you for giving your time and your donations – these are so important to us.

Epilepsy Specialist Nurses, doctors and members of the public for their valuable feedback.

Hello, my name is Grant Wright and I’m the new Training and Staff Development Manager. For the last two years, I’ve also been one of Epilepsy Scotland’s sessional trainers.

My background is nursing and working with adults who have learning disabilities. I was an epilepsy specialist nurse for six years and covered the Greater Glasgow area for this client group. I have always been interested in epilepsy. Among people with learning disabilities perhaps 20-50 per cent may have a diagnosis of epilepsy.

Epilepsy Scotland provides quality education and training for professionals, carers, employers and the general public. We design training to suit the specific needs of our customers. Whether it’s the Scottish Parliament or a small business, our team of trainers deliver training wherever it is required.

Courses are run in our Edinburgh or Glasgow offices. We provide customised training as well as standard epilepsy awareness sessions.

‘Understanding and Managing Epilepsy’ is a half day course. It looks at the prevalence and different forms of epilepsy, seizure types and available treatments. The course encourages group discussions on the appropriate management of epilepsy. It also looks at the need to promote psychological and emotional wellbeing.

Our ‘Managing Difficult Epilepsy’ is a full day course that also instructs and assesses candidates in the administration of various emergency medications.

Along with training, I have been working closely with Epilepsy Link Officer Craig Blair. Together we hold monthly information events across the more rural areas of Scotland. At these events we showcase our current range of information leaflets and provide epilepsy awareness talks. We get to meet existing members and encourage others to join.

These events are an ideal opportunity to ‘spread the word’ as widely as possible and help to break down the myths and misconceptions that still prevail.

For training course details, call Training Administrator Jacqui Telfer on: 0131 226 5458, email jtelfer@epilepsyscotland.org.uk or please call me on: 0141 427 4911.
From January 2010, pharmacists across the UK will be allowed to change the brand of drug named on a prescription and replace it with a different, generic brand. We are calling on the Scottish Government to ensure that people with epilepsy are not automatically switched to generic medication.

Generic brands have to follow ‘bioequivalence’ rules. These allow the amount of active ingredient to vary by 80 - 125 per cent. Epilepsy Scotland advocates people with epilepsy should have consistent prescribing and continue on the same anti-epileptic drug(s) they are currently prescribed.

Following our requests, the Scottish Government accepts there are certain drugs where a switch to a generic equivalent may not be appropriate for all patients. This includes some epilepsy drugs.

Electronic Prescribing

Electronic prescribing has just been launched in Scotland and most GPs have signed up to it. This new system will allow your doctor to send your prescription electronically to your pharmacist. It will help reduce the risk of mistakes with your prescription.

The new system will initially be for acute medication only, such as antibiotics. However, electronic prescribing for chronic conditions such as epilepsy will follow soon.

The electronic and the existing paper system will both run together until everyone is satisfied it works well. Only then will you see a change in the way your medication is prescribed and dispensed. The new electronic system will not change your medication.

Taking the tablets

A new DVD is being made to tell newly diagnosed people what life can be like taking anti-epileptic drugs. Three of our members took part in the filming: Ross Bennet, David Dundas and Mary Nicol. We want to thank them for their contribution. The DVD will be available from October 2009.

Emergency service

The Scottish Ambulance Service has started a major consultation which will influence their strategy and vision for the future direction of the service. They aim to work in partnership with patients and other national and local bodies in making sure the public receives maximum benefit from the ambulance service. The consultation focuses on four key areas for development:

- how to improve access so patients have the right help in an emergency
- improving delivery of healthcare in remote and rural communities
- how best to take forward an integrated transport service
- how to enhance the care provided by the ambulance service.

Epilepsy Scotland plans to work with the Scottish Ambulance Service to develop a new care pathway when people take seizures and need emergency health care. We believe this would improve patient health and reduce the number of unnecessary journeys to hospital.

One key issue is that currently only paramedics are able to administer emergency epilepsy medication when someone takes a prolonged seizure. We would like the Scottish Ambulance Service to explore whether it may be possible to train staff such as Ambulance Technicians and community-based First Responders in giving such medication.

Other discussion points include the training of call handlers, dispatchers, nurses and other staff involved with assessing seizure-related emergency calls. We can also advise on managing situations where people refuse treatment when confused during a post-seizure state.

If you have views or experiences about emergency services that you would like to share, tell Anissa Tonberg, Policy and Development Officer on: 0141 419 1700 or email atonberg@epilepsyscotland.org.uk

http://petitions.number10.gov.uk/epilepsygenerics
Epilepsy Specialist Nurse (ESN) Sheena Bevan has worked in epilepsy care in Grampian since 1997. In her present role along with the islands of Orkney and Shetland she also covers Grampian’s 3,000 square miles. This represents challenges - not least how Sheena and her paediatric ESN colleague deliver a specialist service to people in outlying locations. Sheena explains how finding new ways of working is important so patients can benefit no matter where they live.

“In Grampian patients and their carers are regularly referred to epilepsy nurses for information and support. Less than half (40 per cent) of the population are city dwellers. The remainder live in remote and rural areas.

“My remit is working with Adult Services. This means we can assist approximately 3,846 adults with a diagnosis of epilepsy living in Aberdeen city, Aberdeenshire, Moray, Orkney and Shetland.

“At a time of recession and economic down-turn we all have to tighten our belts. Local health authorities are not exempt from the need to make ends meet in an increasingly difficult economic climate.

“So how do epilepsy specialist nurses stand up to the challenges of financial cut backs? How do we continue a specialist service for those who have epilepsy and their carers, given the lack of finances for service development?

“The need for every epilepsy team to have a specialist nurse is well documented in national (SIGN and NICE) guidelines. Patients hold these nurses in high regard. Yet despite campaigns by the voluntary sector, epilepsy specialist nurses continue to be few in number.

“However, we are a unique, creative and resourceful bunch! We develop new ways of working to benefit patients and carers; working within tight financial restraints yet faced with delivering a specialist service to people whatever their location.

“Epilepsy nurses regularly have patients and their carers referred to them for information and support. In 2008, 186 new patients were referred to the adult epilepsy service in Grampian with around 248 patients seen in 104 nurse-led clinics.

Wasted appointments
“Unfortunately, there is also a negative side to these statistics. Despite an automatic appointment reminder service, 43 clinic slots were wasted by patients who did not attend and a further 14 patients cancelled on the day.

“These 57 half hour slots are the equivalent of nine full clinics! This is reflected in many hospital and community clinics throughout Scotland.

“To highlight the problem of wasted appointments, here are statistics from just seven of Scotland’s Epilepsy Specialist Nurses over the last six months:

January 2009 - June 2009
“A total of 254 patients did not contact the clinic to cancel in time for the appointment to be given to another patient on the waiting list. Of these, 239 patients did not contact the clinic at all. This is the equivalent of 42 full clinics each with six slots.

“Recent NHS figures reveal that missed appointments or ‘no shows’ are higher in Scotland than the rest of the UK. This is a major problem and a major cause of long waiting times and wasted money. We are trying to make life easier by changing how we deliver services but patients too have a responsibility to come to their appointments or where possible cancel so the slot can be given to another patient on the waiting list.

New ways of working
“I work single handed and cover such a vast geographical area. Changing the way I work has released more patient appointment slots and reduced the numbers who don’t turn up. Many of these changes could and indeed are being replicated in other rural or inner city areas. Here are some of the things I do.

Clinics don’t just happen in hospital
“People can attend an epilepsy clinic without leaving home. I’ve introduced an evening monthly telephone clinic. It has proved popular especially with patients who are working during the day and find attending clinic appointments at the hospital disruptive to their work or home commitments.

Telemedicine
“People can now see a nurse via a tele-link from their own town or village. Using telemedicine clinics allows patients on Orkney and Shetland and other outlying areas to access specialist care without travelling hundreds of miles to a specialist centre.

“Supported by a nurse beside them, patients attend their GP practice or local hospital tele-link. They are assessed on a face-to-face screen by nursing or medical staff many miles away. This type of clinic is used all over Scotland.

“I also use the tele-link to teach carers to administer rescue medication. It’s helped me to deliver epilepsy training to GPs and other health professionals.
“Training is now being delivered to rural areas all over the north of Scotland – without me having to leave Aberdeen!

Information
“Sometimes all people want is information and to know someone is there if they need them. I now find sending a letter first with specific information to new patients reduces the numbers who do not attend their clinic appointments. I encourage patients to contact me to request further information.

“They can have a telephone follow-up or a face-to-face follow-up. This allows people to decide if and when they want contact with the ESN.

Training programmes
“Training in epilepsy has helped build confidence in many carers. A customised training programme is delivered by a team of nurses. Over 1,600 carers in Grampian have now been trained in epilepsy care and the effective use of all first line seizure rescue medications.

“A set rescue medication careplan has also been designed and agreed locally for use with adults who require rescue medication. GPs can access blank careplans electronically. As a result, we are seeing a drop in patient admissions to hospital with prolonged seizures.

“Successful intervention with rescue medication led to 193 patients recovering at home without admission to hospital. More confident and knowledgeable carers can better support their family members or clients in the community.

“Along with the local GP with Special interest in Epilepsy (GPsI), there's an on-going training programme for GPs who want to update their epilepsy knowledge. The course has advice regarding patients’ annual review, and prescribing rescue medication.

A recession doesn’t mean services disappear
“A recession can be a time of challenge and change. For nurses (and doctors!) it’s a time to re-think how we deliver services within ever-tightening budgets and waiting time requirements.

“Maybe we all need to look at how we can improve epilepsy services when there is little finance for further development. It’s important to evaluate our achievements, plan how we can move forward and address any short-falls in service, including the problem of wasted clinic appointments.

“We need to challenge patients and their carers to help address this situation and perhaps with a little imagination we can all be a unique, creative and resourceful bunch!”

‘More nurses’ campaign

The Scottish Parliament is still looking at Epilepsy Scotland’s 2008 petition which calls on the government to help increase the number of epilepsy specialist nurses in Scotland. Following Epilepsy Scotland’s evidence to the Petitions Committee, MSPs have decided to investigate the issue further.

NHS Quality Improvement Scotland (QIS) has been asked how it will review health boards’ performance on epilepsy specialist nurse levels and epilepsy services. QIS is recommending new standards where newly diagnosed patients are given a nurse’s contact details and are seen within six weeks. MSPs have also asked whether NHS boards are currently adhering to epilepsy standards. The response will be considered by the Petitions Committee on 21 September.

In the meantime, we are pleased to report that four more epilepsy specialist nurses have been employed in Scotland since the campaign started.
Epilepsy Scotland held a very successful “Epilepsy: Psychological and Social Wellbeing” conference in Edinburgh in May. Consultant neuropsychiatrist Dr Alan Carson from the Royal Edinburgh Hospital chaired the conference. Guest speakers included Housing and Communities Minister, Alex Neil and prominent psychiatrists, neuropsychologists and neurologists.

Research reveals between 15 and 30 per cent of people with epilepsy develop depression and anxiety as a direct result of their condition. The conference examined the links between epilepsy and mental health. It also explored the needs of people with epilepsy in order to maintain good mental health.

Session topics covered epilepsy and cognitive impairment, including memory and concentration; stigma and public attitudes to epilepsy; self management and the psycho-social effects of epilepsy. Workshop issues explored wellbeing and the family, and the role of Epilepsy Specialist Nurses.

Following the conference, Epilepsy Scotland plans to complete a service mapping exercise to identify service gaps which can prevent people with epilepsy getting the psychological support they need.

We would like to work with schools to challenge stigma and discrimination and help young people develop a healthy attitude towards epilepsy. We will continue coordinating support groups across Scotland and help individuals to set up their own groups.

For details of the conference report contact Anissa Tonberg on 0141 419 1700 or email atonberg@epilepsyscotland.org

Mindful of epilepsy

Consultant neuropsychologist Susan Copstick from Glasgow’s Institute of Neurological Sciences shared with MSPs how epilepsy can affect mental health and wellbeing. She was the guest speaker at the Cross-Party Group on Epilepsy’s AGM. MSPs learned that more services are needed in Scotland to provide a wide range of psychological support that can assist people with epilepsy wherever they live.

New members

MSPs Malcolm Chisholm, Helen Eadie, Marlyn Glen, James Kelly and John Park have joined the Epilepsy Group. It is now the largest Group in the Scottish Parliament. To check if your MSP is a member visit: www.scottish.parliament.uk/msp/crossPartyGroups/list.htm

NEW support

National Epilepsy Week 2009 (NEW) was supported up and down the country. Media opportunities included member Jane Williams briefing West of Scotland Bill Wilson MSP while Luss Coach House owner Rowena Ferguson joined Jackie Baillie MSP in raising awareness with an information display. Members helped distribute our new Helpline poster locally. Others sent their health board a campaign sheet calling for more specialist nurses.

In Skye, volunteer presenter Barbara Mackenzie kindly offered the help of community radio station Cuillin FM. Her colleagues supplied a free radio advert on epilepsy that was also broadcast on several local radio stations.

The Joint Epilepsy Council (JEC) of the UK and Ireland had its exhibition stand in the Garden Lobby of the Scottish Parliament. Nearly half of all MSPs (58) took part or had their photos taken at the JEC stand. Chief Executive Lesslie Young attended a successful JEC Westminster lobbying event and met with her own MP, Alan Reid.
It is a really exciting time for Epilepsy Link Officer Craig Blair. He has been in contact with support groups around the country. New groups, including one in Dumfries, are starting up.

One epilepsy support group based in Greenock is extremely proactive in their local community. Recently they contacted their local MSP Duncan McNeil and the Director of Education to discuss delivering basic epilepsy training to all education establishments. This may be piloted through ‘Twilight’ sessions.

It is positive and encouraging to see how support groups can influence change in their own areas.

Information events
Our successful information events, which include awareness talks on epilepsy, have been held up and down the country. These events have raised community awareness and provided help and support to people with epilepsy, their families and carers, especially in more rural areas. It is important to Epilepsy Scotland that everyone has the same access to information, services and care.

This year we reached Ardrossan, Castle Douglas, Dundee, Peterhead, Fife, Fort William, Skye, Kyle of Lochalsh and Orkney. We appreciate all who attended and helped with organising these events, and for the positive feedback. We value all the new members who joined Epilepsy Scotland from these areas.

It’s a date!
Epilepsy Scotland’s AGM and members’ day will be held in Glasgow on Saturday 3 October 2009. Glasgow University’s Wolfson Medical School is our venue and the focus will be on generic prescribing of epilepsy medication. We have invited guest speakers including an Epilepsy Specialist Nurse, GP and pharmacist to give their views on the continuity of supply for people taking anti-epileptic drugs.

The day will include a complementary lunch and refreshments. It will be an opportunity for members to meet staff, board members and guests. For details please contact Epilepsy Link Officer Craig Blair on: 0141 427 4911 or email cblair@epilepsyscotland.org.uk

Inverclyde Epilepsy Support Group
The Inverclyde group have raised public awareness by involving a local college in designing their information poster, arranging guest speakers for meetings and handing out Epilepsy Scotland’s information leaflets. The group has prompted lots of people to sign our ‘More nurses’ campaign!

Support and information
Here are some events we are taking part in:

17 September – Information event, North Berwick
1 October – Cross-Party Group on Epilepsy, Edinburgh
3 October – Epilepsy Scotland AGM, Wolfson Medical Centre, Glasgow
4 October – 5K Big Fun Run, Glasgow
4 - 10 October – Mental health awareness week
9 November – Epilepsy Scotland Art event, Glasgow
2 December – Scottish Parliament reception, Epilepsy Scotland 55th birthday celebration
28 January 2010 – Cross-Party Group on Epilepsy, Edinburgh
14 February – St Valentine, patron saint of epilepsy

Information events and epilepsy support groups are held throughout Scotland. For details please visit our new blog: epilepsyscotlandblog.org.uk or www.epilepsyscotland.org.uk or call: 0808 800 2200.
Dr Freddie Westbrook has been an Occupational Health physician for more than 10 years. During his 12 years as a GP, he also assessed clients for various state benefits and allowances. He then worked for the benefits agency medical service to set up their assessment processes and later moved into Occupational Health. In this interview he explains how an Occupational Health Service supports people with epilepsy in the workplace.

“For me, it’s a natural progression to see how health and work interrelate. Today Occupational Health is a speciality in its own right but there was no comprehensive provision of Occupational Health included when the NHS was created in 1948. It should have been. Instead it has always been seen as an ‘add on’. What is provided nowadays depends greatly on employers. Some organisations buy in occupational health services, some like the NHS provide it “in house” while others may have no Occupational Health provision at all. Occupational Health services are mainly delivered throughout the UK by a mixture of doctors and nurses, with a relatively small number of specialists.

Training and epilepsy

“Learning about medicine and health doesn’t finish when you graduate. We have a responsibility in medicine to maintain our knowledge and be aware of best practice. A lot of work has gone on over the years to develop training modules and guidance for epilepsy. Much of this is clinically orientated, looking at the diagnosis and treatment. Less is written about the employment and occupational aspects of people who have a condition like epilepsy.

“This is one of the areas in the field of occupational medicine that we are trying to push forward. We want to introduce a more evidence-based approach that includes employment outcomes. We’re particularly interested in developing guidance as part of national guidelines for people who have this type of condition. It will incorporate how people with epilepsy, as with other conditions, can be supported into employment and at work.

Support

“Epilepsy is a very common condition but the number of people referred to see me is actually not many. Most of the time people who have epilepsy will be in contact with Occupational Health either at the point of entry into the work environment or if something goes wrong. So the vast majority of people who have a stable, relatively well-controlled condition will not be referred for advice.

“The majority of our enquiries are where individuals declare that they have a health condition at the pre-employment stage. This might be relevant to their employment in the job and advice is given to the employer on that. In a small percentage of cases further evidence is obtained to clarify any issues. We may also offer a face-to-face interview with one of the Occupational Health advisors who is involved in that case.

“The cases I tend to get involved in are where individuals develop epilepsy during their working life. We’ll look at the employment implications this might have and the next steps in how we can help integrate those individuals to continue to perform at work.

Keeping up to date

“An Occupational Health physician often develops expertise in employment sectors rather than specialise in a particular health condition like epilepsy. So there is a variable level of knowledge and expertise; however, practitioners have a responsibility to maintain their knowledge because of medical advances.

“There are various information routes advisors can access. These include the internet, educational modules, for example, the British Medical Journal which produces lots of helpful learning for a whole variety of conditions, and also talking to other relevant professionals or specialists.

Working together

“There are various routes when people come to see us. Some organisations are quite keen for employees to access us themselves. Alternatively the employer may refer people to come and discuss their health issues. An organisation may also ask us for an opinion on an individual’s capabilities to do various tasks.

“Organisations can make a referral to Occupational Health but if the individual doesn’t want to engage in that process they have that right, it is not compulsory. Many of the interactions we do involve getting background information from the person’s GP or neurologist. We can exchange and share information about an individual but only with the person’s informed consent, which is very important.
“One of the things we don’t do enough is act as a second referral from GPs. Essentially our role is to advise the employer and the individual on matters of health. If there is a disagreement, often what can be helpful is actually writing to the GP for a current assessment.

“As a health professional, I try to explain our impartial role to the person who uses our service. I go over what the process involves and obtain their consent to carry out any assessment. People often need time to talk about their condition. Our job is to take a balanced view and to ensure the individual is engaged in any information exchange between us and the employer.

**Overcoming stigma**

“The working environment has obviously changed beyond recognition over the last 50 years or so. Yet for some employers that are considering whether or not an individual is capable of doing a job, there is a stigma around epilepsy and entry into the workplace. It’s rewarding to be able to assure them that the fact someone has this health condition should not be a barrier to most forms of employment. Our advice can help support employers hiring individuals with epilepsy and be proactive about how that person can optimise their working life.

“We know from research that it’s hugely important to be in a meaningful job. Being in work brings long-term health benefits. One of our roles is to give advice on placing an individual in a working environment that’s safe and meets both their needs and the organisation’s needs.

“**What you get is an employer who has a happy employee – and that’s what we’re trying to work towards. Occasionally there are situations with unhappy outcomes but for the vast majority of referrals, our service is able to provide information that brings new or continued employment.**

**Education**

“Part of our role is in educating employers, helping them gain a bit more confidence in moving their goal posts when they see people with health conditions. Where necessary, from our knowledge both of the working environment and the health condition, we can advise on the need for any workplace adjustments or modifications such as working patterns, specific activities, equipment, training, support needs and more.

“We also try to help their employees and potential employees become more confident in dealing with health issues in the workplace. Feedback from our clients helps us better understand how the employer and employee have worked together to find a solution.

“Having information relevant to occupational health is so important. One task I look forward to is helping Epilepsy Scotland produce an accessible guide for employers.

“We need to capture some of the rich evidence about the impact our service makes to the lives of people with conditions like epilepsy and the employment sector. Occupational Health really is a champion service!”

**Little and large champion employers**

A small Glasgow firm of 11 employees, Russell Hamilton Business Systems Limited and the Scottish Parliament have each won Epilepsy Scotland’s Employer of the Year Award. Both organisations demonstrated outstanding support, and their practical, tailored help for staff with epilepsy were praised by the judging panel. They said the Russell Hamilton firm was ‘a classic case of small is beautiful’ while the Scottish Parliament was ‘a beacon of good practice for others to follow.’

This year’s judges were Dharmendra Kanani, Director of the Big Lottery Fund Scotland, Dave Moxham, STUC Deputy General Secretary, Rory Mackail, West of Scotland Chair of the Federation of Small Businesses and Carole Symington, South East Edinburgh Branch Chair of the Chartered Institute of Personnel and Development. Both awards were presented at Epilepsy Scotland’s Wag of Wags dinner in the Glasgow Marriott Hotel before 300 corporate guests.

A free epilepsy best practice certificate is currently available to any organisation following the legal requirements of the Disability Discrimination Act. Just call **0808 800 2200** for a form or visit [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)
“There are no recent laws to help people with epilepsy and more understanding of the condition is needed. Confusion after a seizure is referred to as an “automatism”. During this, a person can wander off and do something without fully knowing. Many people reading this will recognise the brief period of disorientation that follows a seizure. An early account of getting into trouble with the authorities was provided in the 1870s by a French neurologist named Charcot. He described a person with epilepsy who walked onto a train without paying the fare. So this situation is not new and yet people with epilepsy are still at risk of their automatisms being misinterpreted as some type of deliberate antisocial act.

“The law does recognise that automatisms exist but regards those occurring in persons with epilepsy as being “insane automatisms”. Similar episodes that occur in someone with diabetes and a low blood sugar (a “hypo”) are not labelled in this demeaning way. This difference makes no sense. It further stigmatises epilepsy. In fact, the law that uses this terminology is over 200 years old (McNaughten Rules). The legal concept of automatisms needs to be brought up to date. Knowledge about and attitudes to epilepsy have advanced enormously in other areas in recent years.”

Q. What kinds of minor offences are people accused of during/after a seizure?
“Most charges relate to minor offences such as a breach of the peace, adjusting clothing in public, not paying a bus or taxi fare and resisting restraint. Such actions are not planned or premeditated, they are out of character and have occurred in the aftermath of a witnessed seizure.

“People in an automatism cannot carry out a deliberate act such as theft for benefit or seeking someone out for revenge. Automatisms do not lead to serious offences as these have to be pre-planned which will reassure people reading this.

“Curiously, most of the charges I’ve dealt with were exclusively made against men. It seems to me that law officers have a much more circumspect approach when dealing with confused females.”

Q. How do police officers and Crown Office officials learn about epilepsy?
“Usually the accused person brings their history of epilepsy to the authority’s attention. Much depends on how hard they push to get supportive statements from their GP or hospital doctor, what advice their defence lawyer gives and how the Fiscal service relates the role of epilepsy to the offence. My impression is that it is all very ‘hit and miss.’ Many people with epilepsy will plead guilty just to get the stress of it out of the way.”

Q. Are staff in these professions given any training in epilepsy awareness?
“That’s a good question! I am not aware that they receive any epilepsy training. It would benefit the Fiscal service when they have to decide on the medical circumstances surrounding an allegation. Perhaps a Fiscal seeks guidance about pressing for a disorderly conduct charge but there’s a letter saying that the individual has epilepsy and can be confused following a seizure. However, I have never yet been approached by the Police or by the Fiscal service for advice prior to them pressing charges.”

Q. Has epilepsy ever been used inappropriately as a defence?
“There are always some people that will look for a way out of a situation and people with epilepsy, like anyone else, are not always law abiding. There are cases, usually involving serious crime, where epilepsy has been used as a defence. These cases are never successful, usually because the crime is premeditated.”
Q. Will you give an example?
“A good example is Jack Ruby. He shot Lee Harvey Oswald, the probable assassin of President Kennedy. He took a gun to Dallas Police station where Oswald was being held. He waited in the crowd before deliberately stepping out and shooting Oswald in the chest. Jack Ruby may have had epilepsy (even that is disputed) but for his defence lawyer to suggest all this was done during an automatism is unbelievable. The defence failed and Ruby was sentenced to death but died from natural causes in prison.”

Q. What can happen to people with epilepsy charged with a minor crime?
“This can be devastating. We all know that worry and anxiety can affect epilepsy. Many people waiting on a court appearance experience an increase in seizure frequency along with all the inherent family and employment issues that would affect anyone in a similar situation.

“Trial postponements and the long time it takes some cases to come to busy courts just make matters worse.”

Q. What can be done to address the current legal process?
“I would like to see a judicial system which acknowledges that confusion after a seizure can result in unusual behaviour and which does not result in unnecessary charges being brought against innocent people.

“There is still a great deal of misunderstanding of epilepsy; most people only recognise tonic clonic seizures rather than blank episodes coupled with confusion. Most cases I’ve dealt with are evidently due to post seizure confusion. These cases could be rapidly dismissed if early appropriate medical advice is sought. This would save personal suffering as well as the court’s time and money.

“I would suggest a rapid assessment of cases so that the Fiscal, with appropriate medical input, can reach an early decision.

“Police officers and some ambulance paramedics would benefit from epilepsy training to prevent unnecessary charging.

“I am not advocating that people with epilepsy have preferential treatment, or even be above the law. Their cases need to be more fairly handled, with a greater understanding.”

Q. How easy would this be to do and what would it cost?
“It can be achieved simply. The overall number of cases involving epilepsy is not high. Plus there would be potential financial savings in terms of court time and less legal bureaucracy.

“The cases I’ve been involved with have been legal aid funded - many have run on for months. In my experience of 30 cases, only one person was convicted. In none was my medical evidence opposed by an expert representing the prosecution.”

Since launching this new service we have received a number of text messages asking for advice and help.

Remember, it's confidential and you’ll get a response from us within 24 hours.

Why not send us a text next time you want to ask a question?

### Fatal Accident Inquiry

The Procurator Fiscal has agreed to hold a Fatal Accident Inquiry into the sudden death of Fife teenager Erin Casey from a seizure in 2006.

This will be the second Fatal Accident Inquiry in Scotland around epilepsy and both involved teenagers.

The Casey family have been campaigning since 2006 that information is made available to families about SUDEP (Sudden and Unexpected Death in Epilepsy).

A new date for the Inquiry is expected shortly after two dates in September 2009 were postponed.

### Letters and comments

If you want to comment on anything in this issue of ‘Epilepsy News’, please contact Allana Parker, Communications Manager at Epilepsy Scotland, 48 Govan Road, Glasgow, G51 1JL

Tel: 0141 419 1701 Fax: 0141 419 1709 Email: aparker@epilepsyscotland.org.uk

Our newsletter now has a reduced carbon footprint.
Six years old Millie Mackenzie from Dunfermline in Fife has been given the all clear.

The difficult operation to remove a quarter of her brain and end around 20 daily seizures has been successful. Although Millie was in hospital eight times this year having operations to drain fluid from her brain, she is now well at home. Her mother Kelly remarked; “As her neurologist said when Millie’s high temperature reached 40 celsius, it was ‘a true test of her seizure control.’ So much so that her Epilim medication is being reduced. Millie is so much brighter and such a happy wee girl.”

Bigger and better

The Information team has been busy reviewing and writing new publications. A brand new ‘Emotional Wellbeing’ guide was launched at our “Epilepsy: Psychological and Social Wellbeing” conference in May. This has been well received and looks at the emotional impact of living with epilepsy. Many people have told our helpline they find the guide’s practical advice very useful.

We also reviewed and expanded the safety fact sheet into a new ‘Staying safe with epilepsy’ guide. It is already being used by occupational therapists and social workers to ensure that people are safer in their own homes. The guide is packed full of handy hints and tips.

Teachers and parents alike have praised our ‘Epilepsy - a guide for teachers’ publication which replaces the old Teachers factsheet. It clearly explains how seizures can affect a child’s learning and what teachers can do to support a child with epilepsy. Every school in Scotland now has a copy.

We are always keen to hear your views on our publications, and ways to improve them. We also welcome your ideas for new ones. Please contact our helpline: 0808 800 2200 or email: enquiries@epilepsycotland.org.uk

Landmark Disability Decision

A recent ruling from the House of Lords will help protect the rights of people with a disability.

They have decided that those people with a mental or physical condition, such as epilepsy, will still have the protection of the law against discrimination, even when their condition has improved over time and no longer has a significant impact on their day to day life.

The Lords recognised that some conditions can become invisible because they are managed well by medication. In this ruling, they have made it clear that even though a condition is well controlled, it is still a disability and the person is therefore entitled to protection against unlawful discrimination.

This is good news for people with epilepsy. The new ruling has finally put an end to confusion about whether someone with good seizure control is still recognised as having a disability.

This poem concerning epilepsy was written by Mrs Barbara Liddle, Steven’s mum. It was published in her book ‘Reflections’.

For Steven

I have three sons, Tall and strong, With sapling juices in their veins; But more than trees for these are men. I have created them, tissue and bone, Sinew and soul. Loved and berated them, Wept in my mother’s heart For each childhood sorrow and pain; Weeping still for the one in three Who yet needs me. His is the burden, Mine but the watcher’s part. I can do nothing for him – There is no cure. He learns to live with unpredictability, unsure, Never quite knowing the where or when, Yet knowing he will fall again. Life isn’t fair – to give me three And then condemn the one Who means so much to me.
Improving epilepsy care in older people

Consultant in Acute Medicine for the Elderly, Dr Andrew Elder and epilepsy specialist Dr Susan Duncan, both from the Western General Hospital in Edinburgh, are pioneering a new clinic for older people with suspected epilepsy.

They both worked on the recent “Epilepsy in Later Life” good practice guide, produced for Epilepsy Scotland in 2008, and share the view that a shared approach to care, involving both epilepsy specialists and geriatricians, can bring benefits to older people with proven or suspected epilepsy.

Their joint clinic will allow patients to have “one-stop” access to specialist advice, suitable investigations and multidisciplinary assessment if appropriate, thus addressing both the medical and functional problems that often co-exist. As diagnosis is often difficult, the referral entry point is transient loss of consciousness without a clear alternative explanation.

Dr Elder said: “Dr Duncan and I aim to provide a co-ordinated diagnostic and treatment service with access to multidisciplinary input for frailer patients.

“As far as we know, it is the first joint clinic of its kind in Scotland. We will be promoting the clinic to GPs and with hospital colleagues so that older people having an unexplained “funny turn” can be referred to us. It is too early to know just what impact the service can make but we hope it will bridge several gaps in current local service provision.”

Q&A

What are non-epileptic seizures (NES)?
Non-epileptic seizures (NES) are also sometimes called pseudo seizures, psychogenic seizures, pseudo epilepsy or Non Epileptic Attack Disorder (NEAD).

During an epileptic seizure the brain’s normal electrical activity becomes disrupted. With non-epileptic seizures there is no disturbance in brain activity. Non-epileptic seizures may have a psychological rather than a physical cause. They can be caused by depression, anxiety or loss. Some people with NES have experienced abuse or trauma in their lives.

Some people worry that NES suggests they are ‘putting on’ or lying about their seizures. This is rarely the case. Non-epileptic seizures are very real and the majority of people with NES have no control over them. These seizures can be as disruptive as uncontrolled epileptic seizures. NES is treated differently to epilepsy.

A psychologist or psychiatrist can help to identify possible causes and advise on a suitable treatment. This may involve psychotherapy or counselling.

Call 0808 800 2200 for more details or download a fact sheet from our website.

Promising results

Scientists at the University of Leeds have discovered a new way in which epilepsy can be caused and prevented in mice. Researchers have identified a faulty gene that controls the levels of some chemicals such as sodium and potassium in the brain.

An imbalance of these chemicals may be a cause of epilepsy in some people. There is a lot of research still to be done. However, this study may provide clues to potential causes and treatments of epilepsy in people. More details at: www.leeds.ac.uk/media/press_releases/current09/epilepsy.htm

Researching R 20

The Ring Chromosome 20 Foundation presented its latest research findings at the International Epilepsy Congress in Budapest in June. This rare genetic epilepsy condition is characterised by refractory (not responding to drugs) epilepsy, nocturnal subtle seizures, behavioural problems and mild mental impairment. Diagnosis can be missed or delayed due to a lack of genetic testing.

Originally established in Scotland, the Foundation works hard to raise awareness and provide information and resources to affected individuals and their families. More research is needed into better diagnosis and treatment. So it’s good news that the Foundation has awarded three new research grants to scientists from Spain, France and the USA. For more details visit www.ring20.org

Blog away

Epilepsy Link Officer Craig Blair will launch Epilepsy Scotland’s blog site shortly. You can find out what is happening with Craig’s work and know more about our latest events and fundraising activities. Blogs won’t replace websites; they are an informal and an easy way to keep in contact with people who are interested in our work. Epilepsy Scotland’s fans will be linked from Facebook and Twitter. Visit epilepsyscotlandblog.org.uk and follow Craig’s progress on his October challenge to abseil down the 150ft Titan crane in Glasgow and raise money for Epilepsy Scotland!
Matt Bendoris is the Chief Features Writer for The Scottish Sun newspaper. He’s 38 years old and lives in Kilsyth, near Glasgow, with his nurse wife Amanda and their two kids Andrew, six, and three year old Brooke, who has epilepsy. Here, he writes why he was inspired to run the Edinburgh Marathon for Epilepsy Scotland…

“Nothing prepares a parent for their child’s first seizure. When my daughter Brooke took a febrile convulsion at 10 months old, my wife Amanda and I thought she was dying.

“Sadly, it wasn’t a one off. Brooke was hospitalised again shortly after her first birthday, this time with a series of seizures – I lost count at around 23 over three days. She had tests and more tests – in fact we missed out on great chunks of her early life through hospital visits and near constant illness.

“Finally, after many dead ends, she was diagnosed with damage to her chromosome two along with bronchiectasis – scarring on the lungs. In all probability her little lungs were probably damaged after inhaling food while in a seizure.

“Although Brooke is only three years old she’s already been subjected to stigma and prejudice because of her condition; the childminders who won’t return your calls, the nursery who cites a lack of space because of staffing issues related to her epilepsy. It’s been both tough, upsetting and a real eye-opener.

Raising Awareness

“That is why I wanted to try and raise awareness of epilepsy. Epilepsy Scotland became my charity of choice from the Just Giving site when I decided to run my first marathon this year. I actually found fundraising much easier than training, even with the early morning runs in icy training conditions with my one year old black Labrador Katy.

“I had tremendous support from my colleagues, especially when I explained in an all-round email - which not so subtly included my Just Giving link - what Brooke had been through. I genuinely think her story helped. Many people would tell me they didn’t know about Brooke’s problems – well it’s not the type of thing you chat about while making small talk at the water cooler. But I was surprised by the number of folk who said their own kids or relatives had epilepsy too.

Finding support

“So it helps to be personal when fundraising, and donating through Just Giving couldn’t be easier. My company, News International, also donated a further £1,000 to the cause. And I called in a few favours with rich and famous celebrities I’d met over the years too. Ultimo bra tycoon Michelle Mone donated £200. The Proclaimers gave me £300 and the lovely GMTV star Lorraine Kelly stumped up £100. When it was all put in the pot I’d raised £3,249.38 for Epilepsy Scotland.

“But with that sort of money comes pressure. When my left knee began to pack-up there was no question I could pull out of the marathon. I just had to find a good physio in the shape of former Celtic backroom man Brian Scott who soon patched me up in time for the race.

“In the end I completed the 26.2 miles around Edinburgh on May 31. How did I feel? Slightly disappointed to be honest. I’d been training to beat the four hour mark, but came in at 4 hours 8 mins. Eight minutes isn’t that long you may say? Well it was long enough to make me immediately sign up for the Amsterdam marathon on October 18 this year – and this time it’s personal.

Going on

“As for life now, well it’s a lot better. We’ve got Brooke into a great nursery – Cumbernauld College Nursery – where the staff have been magnificent with her, encouraging both our daughter and ourselves.

“It’s a shame we had to go private but the state school just wanted to pigeonhole Brooke and send her off for special education. And less said about the pre-five support teacher who branded our little girl ‘lazy’ the better. Sure, it’s tiring having to fight for everything, but she’s worth it. We are determined to see Brooke join mainstream schooling, even if the system seems to think otherwise.

“Her seizures have become few and far between and her health continues to improve, meaning she’s now enjoying a more normal childhood. What the future holds is anyone’s guess. But she’s a gutsy soul and fiercely independent with plenty of character - she had to be to survive. In fact compared to everything our wee girl has been through, running a marathon was easy peasy.”
Commemorating Scott

We would like to thank Scott McCallum’s family and friends for raising over £1,000 for Epilepsy Scotland in memory of Scott, who died last summer. Friends, relatives and colleagues held a benefit night at the famous Horseshoe Bar in Glasgow where he worked. Over 25 people also took part in a sponsored walk around Strathclyde Country Park to commemorate Scott.

We are very grateful to the McCallums for helping us to carry out our vital work by holding these events in his memory.

Grin and bear it

Our warmest thanks go to Mairi Russell and Cranberry the Teddy Bear after completing a 400 mile sponsored cycle through the Margaret River region of Western Australia.

The challenge took nine days over gruelling terrain and Mairi and her trusty sidekick Cranberry raised over £400 for Epilepsy Scotland.

The amount of daily cycling varied between 30 and 60 miles. Mairi completed some of the ride in a red wig and feather boa and the pair were even featured on Australian television! Both have recovered from their adventure, though we understand Cranberry needed a cycle of his own – in a washing machine, that is.

Donations in memory

Since the last newsletter we have received the following donations:
- £1,075 from the funeral collection of Mr Tom Farrell of Dundee
- £360 from the funeral collection of Thomas Cullen in Musselburgh
- £200.10 from the funeral collection of Ms Kathryn (known as Kay) Farish of Inverness
- £210 from Forfar Academy in memory of 4th year pupil Christina Ilia. A retirement collection was taken at the spring concert, at which Christina would have performed
- £100 in memory of Eileen Wright of Rosyth from her sister Jennifer Gibson
- £50 from Mrs Sarah Gilmour in memory of her late husband Mr R G Gilmour who had supported our work for many years
- £550 received in accordance with the late Margaret Wilson’s wishes
- £50 from the funeral collection of Lynn Ruff of Crieff.

Festive Fair

Our first Christmas Fair will be held at the Trades Hall, Glassford Street, Glasgow on Saturday 31st October. Epilepsy Scotland merchandise will be available plus many other charity stalls, selling Christmas cards and decorations, gifts, crafts, fancy goods and handmade jewellery. The Fair will run from 10am – 3pm, with a tea room for yummy treats and free entry all day. Please join us!

A night for Colin

Special thanks to Scott Blair and friends who organised a special fundraising night in memory of Colin McInally, who died of epilepsy in November 2008.

The glitzy black-tie night at The Corinthian, Glasgow was attended by all of Colin’s friends and family and raised a staggering £2,400 for Epilepsy Scotland’s vital services.

Cousins Cameron and Callum, both 13, raised over £300 of this by hitting the streets with their sponsor forms and Epilepsy Scotland t-shirts. Our thanks go to the whole family.

Powell power

The Powell Family are long time supporters who recently did a sponsored walk around Edinburgh in aid of Epilepsy Scotland. The walk was part of the “Walk for Scotland” event and the Powells – joined by four-legged friends Murphy, Milo and Patch – raised £542!

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Wag of Wags

Epilepsy Scotland held not one but two special ‘Wag of Wags’ dinners earlier this year. The glitzy gala nights were held at The Balmoral Hotel, Edinburgh and Marriott Hotel, Glasgow. Winners from the last five dinners in each city competed against each other to entertain the crowd and be voted “Wag of Wags”. 600 corporate guests attended fundraising dinners and helped to raise a terrific £73,000.

In Edinburgh, celebrity Chairperson Grant Stott presented Janey Godley with the ‘Edinburgh Wag of Wags’ trophy after she was chosen over Alan Rough, Eric Davidson Rod MacCowan and John Htet-Khin as the audience’s favourite speaker.

The Glasgow dinner was chaired by BBC sports star Chick Young. Renowned after-dinner speaker Sandy Strang triumphed after seeing off some tough competition from Bert Thomson, Hugh Brown, Bruce Fummey and Brian Donald.

Thank You

Our supporters continue to amaze us with their generosity – here is a selection of some recent donations:

- £444 from Carluke High School as part of their Charities Campaign, which raised a stunning £21,600 that was distributed to 40 charities
- £500 from Ayr College raised by students at the Equal Cafe from baking cakes and running coffee mornings for the students and staff
- £700 from Robert and Liz Irvine who asked guests at their Silver Wedding Anniversary to donate in lieu of gifts
- £206 from Job Centre Plus at Leith, Edinburgh, raised at their recent dress down day
- £586 from Douglas Sneddon and son Cameron from completing the Dundee Cyclathon
- £208 from Robin Harte who walked the West Highland Way
- £1,400 from Robin Gordon who used his 50th birthday to fundraise for us.

Day out for the girls!

After last year’s event, Epilepsy Scotland is announcing another fabulous Ladies Lunch on 25th October 2009!

The lunch will be held in the gorgeous surroundings of Pollokshields Burgh Hall, Glasgow. Guests will enjoy a cocktail on arrival, followed by a beautiful two course lunch catered by Guy Cowan of Guy’s Restaurant, Glasgow. The afternoon includes a fashion show, great entertainment and lots of goodies to be won. Join us for some excellent food and fine wine, latest fashion, fun games and a glitzy auction.

Tickets will soon be available. Call: 0141 419 1707 to snap up yours!

Art from the heart

Epilepsy Scotland’s Art Sale and Auction in Glasgow in November 2009 will feature even more paintings, photographs, ceramics and jewellery from some of Scotland’s finest artists and jewellers.

There will also be Christmas goods and plenty of choice crafts and gifts to suit all tastes and budgets.

This annual event is a firm favourite with hundreds of our supporters and last year raised almost £20,000. The date and venue will be confirmed soon – so please keep an eye on our website for further details!

Get in touch!
If you would like to fundraise for Epilepsy Scotland we would love to hear from you. We can help with ideas and give you sponsorship forms to make it easy to raise funds. Call 0141 419 1707, email: fundraising@epilepsyscotland.org.uk or visit: www.epilepsyscotland.org.uk