Welcome to the interactive version of our annual review 2012. You’ll notice the icons below used throughout the review. Clicking on the icons will enable you to:

- link straight through to our website or YouTube channel
- see more images or text.
2012 has been a milestone year for Epilepsy Society. Not only have we celebrated our 120th birthday but we have opened the doors of our brand new Epilepsy Society Research Centre. This year’s annual review represents our past, present and future, from precious archive photographs and documents, current campaigns and projects, through to a new era in research and the diagnosis of epilepsy. We hope you enjoy it.

‘Happy 120th! It’s wonderful to see all that the Society does to support people with epilepsy. I’m from Australia. Isn’t this global village fantastic!’

Fiona, Australia
Celebration and collaboration have been the themes for 2012! It’s been a year of jubilation in the UK – and here at Epilepsy Society our 120th anniversary has given us some extra special reasons to celebrate.

Our celebratory year got off to a flying start with a reception at 10 Downing Street hosted by Samantha Cameron, with an impromptu visit by our vice president, prime minister David Cameron.

Throughout our 120 year history Epilepsy Society has been a driver of innovation. We’ve always sought to secure the best deal for people affected by epilepsy. The changing political and NHS landscape has been a catalyst to reviewing how we achieve the most impact.

We’ve always been believers in the power of many voices. We recognise that epilepsy is one of many neurological conditions – all clamouring for the same attention and the best services. But economic realities mean that resources in the NHS are scarce.

Epilepsy Society – or the National Society for the Employment of Epileptics as it was initially known – was established in 1892 to provide a safe haven for people with epilepsy. In 2012 we still provide the very best homes with state-of-the-art facilities for those with complex epilepsy. But our mission has changed. Today we work alongside the half a million people with epilepsy across the UK to enable them to live as full a life as possible.

But with localised health commissioning groups we are finding that the distinct differences between epilepsy and other neurological conditions are being recognised by commissioners when epilepsy is presented as part of the broader challenge of addressing neurological conditions. That is why we have continued with our affiliated partnership with Neurological Commissioning Support (NCS) and have become members of the Neurological Alliance.

We have also formed a strategic alliance with the charity Epilepsy Bereaved – working in partnership on commissioning of health services, campaigning and research.

Our work with NCS has resulted in the appointment of the first ever ‘national’ epilepsy specialist nurse. Employed by Epilepsy Society, funded jointly with Epilepsy Action and working with NCS, this ‘super nurse’ will work in an advisory capacity as a catalyst for change. A truly collaborative project.

Sarah Vibert (left) has joined Epilepsy Society as our new head of development and policy.

Professors Ley Sander (pictured, left) and John Duncan started as research fellows at the Chalfont Centre on the same day in February 1985.

'I have seen how much work Epilepsy Society is undertaking to improve the lives of people affected by epilepsy. I have a real commitment to help you.'

David Cameron, prime minister

This year we said a sad farewell to one of our oldest residents Bertie Lombard (left) who died at the age of 95. Bertie had lived at the Chalfont Centre since he was 14.

Graham Felkins (right) made many of the bricks used to build the Chalfont Centre (see front cover).

Epilepsy Society Annual Review 2012
The importance of information was recognised very early on at Epilepsy Society, with the production of leaflets to support new residents at the Chalfont Centre. Today we distribute information across the UK on everything from seizure control to employment issues via leaflets, our website, YouTube and mobile phones. And we still value the opportunity to meet face to face with supporters at occasions such as our annual conference.

This year we realised a long-held ambition to produce a resource specifically for people at the point of diagnosis. We recognise that this can be a difficult time both for the person with epilepsy and those close to them. We wanted to produce a resource that would help people understand more about the condition, how it might affect their lives and how they could manage their seizures. Thanks to support from a pharmaceutical company, we have been able to do this. ‘Just diagnosed’ has been produced in partnership with people with epilepsy and we are really proud of it.

We have also been developing our free app to make it an even more useful resource for anyone with epilepsy. Our Android and iPhone apps already provide information and support including a seizure diary and first aid information. Now our latest iPhone app, ‘Epilepsy toolkit’ includes an alarm that can be programmed to remind you to take your tablets. And you can record the name, dosage and a picture of your tablets.

Anyone with a Smartphone can also gain quick and easy access to information or videos on our website via our QR or ‘quick response’ codes. These frequently appear in our leaflets, magazines and on posters. For example, scanning the QR code on our first aid poster will take you to our YouTube channel recovery position demonstration video.

Away from the high-tech world of mobile phones, our conferences continue to provide an excellent opportunity for us to meet and communicate both with people with epilepsy and with healthcare professionals. At our annual conference in September, speakers included our medical director Professor Ley Sander and lead geneticist Professor Sanjay Sisodiya who spoke about the latest research into epilepsy and getting the right treatment.

But among the most important speakers were our delegates. The conference provides a unique platform for anyone affected by epilepsy to take to the podium and talk about their own experiences. It is a moving and valuable experience – a true sharing of the impact that epilepsy can have on a person’s life. Your words help to inform our work. Thank you.

Ben O’Keefe
Epilepsy information services

Download our epilepsy app by scanning the QR code.
The establishment of the National Society for the Employment of Epileptics was a campaign in its own right, born out of a need to provide a better life for people with epilepsy. One hundred and twenty years later, campaigning is very much central to our work as we strive to make the voices of people with epilepsy heard and to secure a fairer deal for all those with the condition.

External factors can play a significant role in campaigns – and none more so than in 2012. We have responded to the proposed government reforms to the health, social and welfare acts by broadening our campaigning platform. Opportunities to comment and respond to changes in policy have been coming at us thick and fast. But uppermost in our mind is that we represent the voice of people with epilepsy.

Collaborative working has been key to making sure the government is listening to the needs of people affected by epilepsy. We work alongside the Disability Benefits Consortium, a national coalition of more than 50 health and disability charities committed to working towards a fair benefits system. Together we are working to ensure government policy reflects and meets the needs of people with epilepsy.

One of the key factors in seizure control is accessing the right care. The changing landscape of the NHS means that services will be commissioned at grass roots level. We want to ensure that people are empowered and equipped to find their way through the NHS maze. With that in mind we have launched our epilepsy charter setting out patients’ rights and choices drawing on information from the NHS Constitution and the NICE guidelines.

During National Epilepsy Week we ran our ‘I’m one in a hundred’ poster campaign which featured Brentford footballer Leon Legge and student nurse Jasmine Smith. Our aim was to raise awareness of just how common epilepsy is.

At the end of 2012 we set the wheels in motion for our bus campaign. We are lobbying the government for a change to the current disabled person’s bus pass. We want to see free bus travel extended in England to include peak time travel and a free companion bus pass where needed. These concessions already exist in Scotland and Wales. Our campaign includes an e-petition on the No 10 website and lobbying tools at www.epilepsysociety.org.uk/bus.

On 11 April 1892 Hughlings Jackson (above), the father of neurology, proposed creating a home for people with epilepsy to provide them with a more positive way of life away from Victorian institutions. Provision of employment was key (below) as was fresh air, nutrition and medication.

Today Epilepsy Society campaigns for a better life for more than half a million people with epilepsy. But many of the challenges are the same: employment issues, better seizure control and a fairer deal for people with epilepsy.

We are hoping 100,000 people will sign our e-petition calling for free bus travel before 9.30am for people with disabilities and a free companion pass where needed.

"Your bus campaign is close to my heart. My bus to work is due at 9.31am – it turns up early some drivers say "why should you get on one minute early and not pay when other people do?" They make me feel very embarrassed. I have sent the link to the e-petition all over my facebook.

Jo-anne, Leeds
In the early part of the 20th century, medical staff noted the positive impact that peer support had on the well-being of those at the Chalfont Centre. Today our fast-growing online community provides a vital network of support and communication around the world. Everybody’s talking and the results are incredible.

This year our online community has grown beyond all expectations. Everyday we are privileged to enjoy a virtual conversation with our supporters that often reaches around the globe.

We now have more than 2,500 followers on Twitter, over 3,000 on Facebook and 9,500 members on our forum. And the community just keeps growing. It is fast, immediate and provides a vital support network for people affected by epilepsy. We not only promote the services we offer but also help people find the information they need. We also support our fundraisers in the lead up to events.

Our epilepsy app has been downloaded by 15,000 people worldwide this year. In June we received a tweet from Cardiff mum, Julia McMullen who said: ‘your iPhone app with first aid guide helped me resuscitate my 3 year old epileptic daughter yesterday #ThankYou’. Julia had been reading the first aid information on our app just the day before and thanks to this was able to give her daughter, Carys, ‘rescue breaths’ while waiting for the paramedics to arrive. Julia has since become an associate member of Epilepsy Society and continues to stay in touch with us through Twitter.

During National Epilepsy Week in May, we launched a series of videos about different seizure types which have had more than 21,700 views. Our most popular video is our recovery position demonstration, which has been viewed almost 15,000 times. Since we launched our YouTube channel in May 2011, we have had over 45,000 views. Many of our supporters are now uploading their own videos to YouTube and sharing their experiences of epilepsy online.

Our website has more than 40,000 unique visitors a month — with approximately 18 per cent of visitors viewing the site from a mobile device. But the website has not kept pace with new technology and is not designed for mobile devices. So we are developing a new website which will enable us to engage more easily with supporters everywhere while continuing to be the most informative epilepsy website across all platforms.

Karen Cornes
Marketing and digital manager

Simone Clarke (below, left) had 20 seizures as she ran the London Marathon with her friend Tally Hall (right). News coverage of Simone’s story through newspapers, Twitter and Facebook saw her fundraising for Epilepsy Society rocket from £800 to £10,828.

“You have no idea what it feels like to get to my age, having achieved very little in life, and then suddenly to have your art work on show.”

Julia McCullen who saved her three-year-old daughter Carys’ life using first aid information learned from Epilepsy Society’s app.

In the early days of Epilepsy Society, getting connected was far more difficult. Visitors to the Chalfont Centre by rail were advised to write and ask matron to send a ‘fly’ — a horse drawn carriage.

Cyclists should look out for the landmark obelisk...

For many people arriving at the Chalfont Centre, it was the first time they had met anyone else with the condition. ‘The improvement in the expression of the faces since admittance is most marked... there is always the utmost readiness and even anxiety to assist each other when a fit occurs.’

Charity Organisation Review 1895
In 1907, when William Aldren Turner published *Epilepsy – a study of the idiopathic disease*, based on his research at the Chalfont Centre, the word ‘gene’ had yet to be coined. This year, little more than a century later, we have just opened our brand new Epilepsy Society Research Centre where we will be carrying out groundbreaking research into genetics and brain imaging.

It really is a dream come true. Finally we have opened the doors of our new £3.4million Epilepsy Society Research Centre, a development that will enable us to carry out the most advanced epilepsy research in Europe and translate it into clinical practice. It really is a dream come true. Finally we have opened the doors of our new Epilepsy Society Research Centre.

The state-of-the-art two-storey building has been made possible by the generosity of charitable trusts and donors who, like us, are dedicated to pushing forward the boundaries of research into epilepsy.

The centre integrates research with our medical unit, magnetic resonance imaging (MRI) suite and therapeutic drug monitoring unit. It offers a spacious laboratory, four new consulting rooms, offices, a library, seminar room and video conferencing facilities. But above all it offers new hope for people with epilepsy.

For 70 per cent of people with epilepsy, anti-epileptic drugs can control their seizures but a further 30 per cent do not respond to medication.

Our research focuses on two distinct areas: brain imaging and genetics. You can read about some of our current research projects over the page.

But one of the most significant innovations at Epilepsy Society Research Centre will be the installation of a DNA sequencer. This has the potential to revolutionise the way we diagnose and treat epilepsy based on a person’s DNA sequence or genome. It is our passport to the future and our gateway to earlier diagnosis and more targeted treatments.

When our neurological forefathers founded Epilepsy Society in 1892, their vision was to provide a better life for people with epilepsy. Fresh air, nutrition and regular medication were key. Our vision today is to unravel the complex genetic architecture of the epilepsies and to take new discoveries directly to patient care. This way we hope to improve the lives of everyone with epilepsy.

We believe that research represents the best hope of finding a cure and eventually preventing epilepsy altogether. Epilepsy Society Research Centre is key to this vision.
Our research

Epilepsy Society works with the NHS University College London Hospital Trust (UCLH) and University College London (UCL).

Risk from Sudden Unexpected Death in Epilepsy (SUDEP)
We are hoping to identify gene changes which could increase a person’s susceptibility to SUDEP. Our aim is to be able to offer those who may be at risk the chance to take potentially life-saving preventative measures.

Ketogenic diet
We want to find out why some children respond well to the high fat, low carbohydrate, protein-controlled ketogenic diet. We want to explore the possibility of reproducing its effect without the need for radical dietary changes.

Array Comparative Genomic Hybridisation (aCGH)
A grant from the Freemasons’ Grand Charity is enabling us to use this test to look for parts of a person’s genome that are missing or duplicated, causing epilepsy and other problems. Our aim is to find the right drug at the right dose for each person from the point of diagnosis.

Epilepsy Navigator
This is a sophisticated form of ‘smart surgery’ which we hope will lead to even safer epilepsy surgery, improved chance of seizure freedom and reduced risk of damage to vital functions such as language, memory and vision.

epilepsysociety.org.uk/research

Main picture: Professors Ley Sander and Sanjay Sisodiya with members of our research team.
Our original mission was to educate those at the Chalfont Centre with skills that would enable them to work in the fields, in carpentry, the laundry or sewing. Today we provide information and support for people with epilepsy in hospital clinics and at health and awareness raising events across the whole of England. This year we have launched an exciting project working to improve the health of people with epilepsy in some of the most disadvantaged communities in London.

Thanks to funding from the Department of Health, we have been able to launch a three-year community development project in six boroughs in north and east London. We are working in communities where there is little understanding about epilepsy, and myths around the condition still exist.

Focusing on black, Asian, and other minority ethnic groups, the project – Epilepsy awareness and your community – is promoting early interventions by raising awareness of epilepsy and identifying the barriers that might prevent people accessing appropriate medical services. We hope this will lead to better seizure control and lessen the impact of the condition on people’s lives.

The project is being piloted in Hackney, Haringey, Islington, Newham, Tower Hamlets and Waltham Forest. From this work we aim to develop a model of intervention that can be used in other parts of the UK.

We have nine regional managers and more than 200 volunteers throughout England. Our regular volunteers are worth more than £295,000 to us each year.

We have spoken to people from Turkish, Kurdish, Somalian, Charedi Orthodox Jewish, Indian, Bangladeshi and Chinese communities.

Sharmin Shajahan, community development manager and Soraya Bowen, community development officer, have already been enthusiastically received in several communities where they have held bilingual epilepsy awareness education workshops within Bangladeshi, Indian and Chinese communities.

They have been speaking with a mental health group in Newham, a patient participation group in Hackney, the Hackney practice managers’ forum, and organisations representing Turkish, Kurdish, Somali and Charedi Orthodox Jewish communities.

They have also taken epilepsy information to Newham ESOL (English for Speakers of Other Languages) Exchange and local events promoting and supporting better health for men and for people with learning disabilities in Hackney.

epilepsysociety.org.uk/community

All the children are taught drawing and painting, gardening, plain and fancy needlework, knitting and crochet and the older boys and girls are taught housecraft subjects, including cookery.

‘A large number of ex-pupils are now doing well in outside life, earning a good livelihood... clerks, engineers, porters, coal miners, farmworkers and among the girls, dressmakers, factory workers, servants and shop assistants.’

Miss KM Robinson, head teacher 1921

We have taken our schools epilepsy awareness programme to 23,000 children across the country, including 5,700 this year.

80 people from the Bangladeshi, Indian and Chinese communities attended five bilingual epilepsy education workshops.
I feel particularly privileged to have been appointed medical director of Epilepsy Society in this, our 120th year. When the organisation was founded in 1892 the outlook for people with epilepsy was bleak. There were no anti-epileptic drugs (AEDs) as we know them today. Bromide salts were the only medication available. Those with seizures often ended up in the workhouse, gaols or institutions for the ‘incurably sick’.

The founding of the National Society for the Employment of Epileptics changed all that. The Chalfont Centre offered an alternative and positive lifestyle with regular medication. The results were remarkable.

In 1895, a report from our then medical director stated: ‘They – the colonists – have realised the great improvement in their health... the number of fits is greatly diminished.’

One hundred and twenty years later and our reputation extends worldwide. Yet diagnosis still remains one of our greatest challenges. For those with uncontrolled seizures the importance of an epilepsy specialist centre such as ours is paramount. This year more than 1,000 people were admitted to our Sir William Gowers Assessment Centre where sophisticated diagnostic techniques enable us to investigate why one third of people with epilepsy fail to respond to AEDs.

Brain imaging in our MRI unit enables us to see deeper into the brain than ever before, helping us to identify those who might be suitable for epilepsy surgery. Video telemetry enables us to identify those people who are walking round with a diagnosis of epilepsy when in fact their seizures may not be generated in the brain.

Today we have more than 20 AEDs to choose from with some of the newer drugs proving to be better tolerated than earlier medication. One recent development, for instance, has been the licensing of Perampanel, a drug with a new mode of action which may offer a treatment option for some of those with uncontrolled focal seizures.

Yet still the holy grail is a cure for epilepsy. In my lifetime I would like to see us develop disease modifying drugs that don’t just treat seizures but which treat the epilepsy itself. But there is a long way to go.
In 1909 a group of ‘colonists’ asked if they might travel to Lords to see England play Australia at cricket. After careful consideration the request was turned down. Today many residents are members of Arsenal Football Club, others sail or horse ride and a large group of residents, including the Phoenix sports team, attended the Paralympic ceremony in Stoke Mandeville this summer.

When Epilepsy Society was founded 120 years ago the vision was all about enablement – enabling people with epilepsy to work.

Today, even though the needs of residents are far more complex than their Victorian predecessors in the days of philanthropist Passmore Edwards (right), enablement is still at the heart of everything we do.

Key to enablement is the ability to communicate – and that’s very much been a focus of our work this year – enabling service users to have a voice and to understand, by communicating closely with individuals, what a full life means to them.

For those with a range of complex disabilities, as well as epilepsy, that can be challenging. Words are rarely enough and identifying individual needs and aspirations is not straightforward.

But thanks to a range of new initiatives, training, and support from our in house therapy team, staff are able to communicate with residents in a host of new ways.

Karen Lane
Director of services

‘It was amazing’
Duncan, talking about his trip with friends to the Paralympic torch ceremony at Stoke Mandeville.

‘Two residents suggested we should hatch and raise chickens. They will be a lovely addition to our sensory garden.’
Jenny Davison, house manager

Makaton is a form of sign and body language used with people who have cognitive impairment. Another tool ‘Widget’ is a system of simple pictures that can be used to communicate. The Widget images can also represent more complex issues like feelings and can give residents a visual reminder of their schedule for the day.

And thanks to a new ‘Dynavox’ computer system residents with multiple needs and even the most limited movements are able to voice their opinions and communicate their wishes.

Epilepsy Society is a truly amazing charity – and one of the highlights of the year was the amazing day in June when residents, former residents and staff joined together to celebrate our 120th anniversary.

With a history spanning three centuries, Epilepsy Society has come a long way, but our core values are still very much central to improving the lives of everyone affected by epilepsy.

epilepsysociety.org.uk/care
For many years the term ‘helpline’ was unheard of at Epilepsy Society. The need for emotional support was barely recognised. Indeed when our Helpline was set up in 1990, its aim was to provide information for professionals. Today we provide information, time, space and emotional support for anyone affected by epilepsy including those with the condition, their family, friends, carers and professionals.

Year on year the number of calls to our Helpline has grown with people wanting information, support, a listening ear and a chance to talk – often for the first time – in complete confidence, often about previously unspoken concerns.

We have always been aware of the missed call rate and the fear that those who need us most – possibly at a time of crisis – may not call back. This year, thanks to a grant from the James Lewis Foundation, we have been pleased to be able to extend our Helpline hours and increase our Helpline team.

Since the beginning of April we have been piloting extended hours for one hour each morning from 9-10 am and, since October, one evening a week on Wednesdays from 4-8 pm.

It’s early days yet, but we are getting calls during the new hours and positive feedback. One caller told us: ‘An evening service is useful as it is difficult to find somewhere private to ring you during the day at work.’

In May the Helpline received the helpline quality standard mark by the Helpline Association – for the second time. When the Helpline Association produced its first directory in 1996 there were around 500 helplines registered. Today there are 1,500. The number of calls taken in 1996 totalled around 6.2 million. This has now increased to 8.7 million calls.

In 20 years we have gone from taking a few calls a day to around 25 calls each day. The average call time has doubled to around 17 minutes, reflecting the complexity of calls. Epilepsy can be complicated and often hard to understand even when good information is available. We listen to our callers and place great value on what we hear.

All calls are completely confidential. There is no time limit to each call so that the layers of complexity can be unravelled and perhaps an understanding can begin.

We know that together we can make a difference.
We have a proactive supporter stewardship programme which I believe has been key to our recent success. The concept of stewardship is becoming increasingly important in the world of fundraising. We value our supporters and mean it when we say we could not manage without their gifts. We want relationships to grow and last. First and foremost we need to find out what motivates people. That’s a two way thing. What aspects of our work are supporters most interested in and how do they want their gifts to make a difference?

It's real life stories and the lengths that our supporters go to when raising money that keep the fundraising team motivated on a daily basis. We all share stories and successes. I remain cautiously optimistic about the future. I think there will still be challenging times ahead, certainly for trust and legacy income. We must continue to be creative in identifying new income streams and fundraising opportunities.

In a year when Epilepsy Society has bucked the national trend of falling voluntary income, we've taken a long hard look at what has contributed to our success. Our latest annual accounts show that fundraising costs have fallen by around five per cent, yet voluntary income has risen by more than 15 per cent. This has enabled us to increase our expenditure on charitable services such as our Helpline, regional services and information resources, by around 20 per cent.

This is a significant achievement, not only in view of the current economic climate, but also the recent downturn in legacy income.

About a year ago the charity took a strategic decision to invest more resource in social media. The result has been a growth in our online community, helping us broadcast our message faster, be more responsive, and enabling us to have an ongoing conversation with our supporters.

In 1905 our records show how the generosity of philanthropist Passmore Edwards turned the dreams of neurologists into bricks and mortar for people with epilepsy. In 1942, the birth at the Chalfont Centre of a calf with ‘V’ for victory on her forehead proved a great fundraising potential! But today it is the collective effort of all our supporters that enables Epilepsy Society to reach out across the UK.
Summary of financial information for year ending 31 March 2012

Total Income £000s
- Residential and nursing care services 9,056
- Donations, legacies, grants and events 3,036
- Rents and other activities for generating funds 881
- Medical services 2,602
- Other charitable activities 1,437
- Investment income 4
- Gain on sale of assets 65
Total incoming resources 17,081

Total Expenditure £000s
- Direct charitable expenditure 14,829
- Governance support costs 34
- Fundraising and publicity 827
- Cost of trading and other costs 488
Total resources expended 16,178

Summary of Epilepsy Society’s balance sheet 31 March 2012 £000s
- Fixed assets 30,285
- Current assets 3,690
- Creditors: amounts falling due within one year 1,803
- Net current assets 1,887
- Creditors: amounts falling due after one year 7,429
- Pension scheme deficit 5,023
- Net assets 19,720

Trustees’ statement: the summary of financial information has been extracted from the most recent annual report and audited accounts, which can be obtained from our head office (see address on back page) or by visiting the Charity Commission website at www.charity-commission.gov.uk and searching under our registered charity number 206186, or the name Epilepsy Society.

The information presented is to provide an overview of the scale of the Society’s activities.
Caress 4
Welcome 2
Cares 4
Informs 6
Connects 10
Campaigns 8
Researches 12
Connects 12
Educates 16
Diagnoses 18
Enables 20
Listens 22
Fundraises 24
Finance 26

www.epilepsysociety.org.uk
Cares
A full life for everyone affected by epilepsy.
Informs
Website, leaflets, dvds.
Researches
Pioneering medical research.
Campaigns
Shaping the future of epilepsy.
Connects
Forum, Facebook, Twitter, YouTube, app.
Volunteer, become a member, fundraise.
Educates
Awareness, schools, training for professionals.
Diagnoses
Specialist diagnosis and medical treatment.
Enables
Expert support, care and respite for complex epilepsy.
Listens
Helpline 01494 601 400
Monday to Friday 9am to 4pm
Confidential. National call rate.
Information and emotional support.

Epilepsy Society
Chalfont Lane, Chalfont St Peter, Bucks SL9 0RU
01494 601 300

Epilepsy Society is a trading name of the National Society for Epilepsy, registered charity no. 364158.