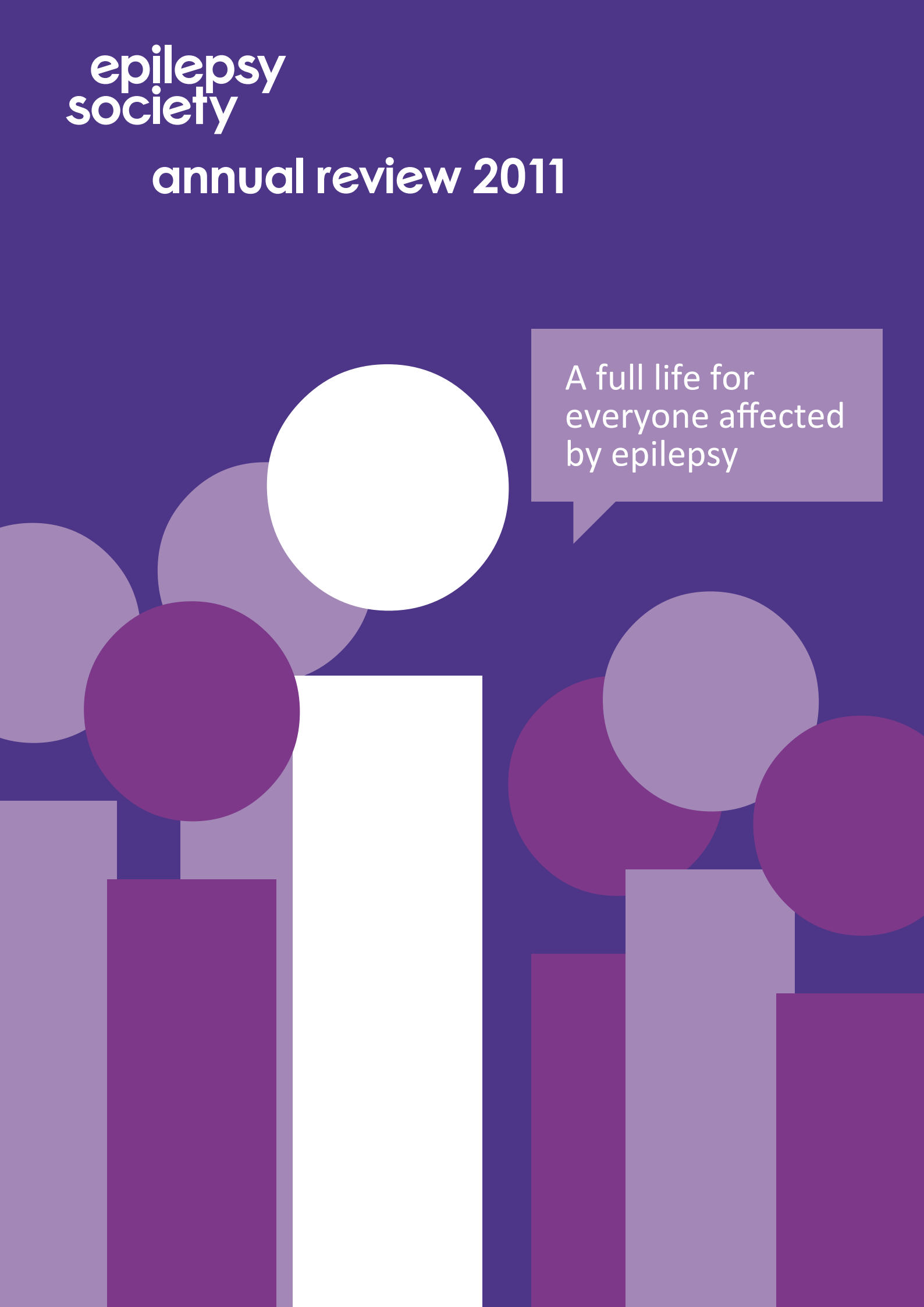


epilepsy
society

annual review 2011

The background features a dark purple color with several overlapping circles and vertical bars in lighter and darker shades of purple. A prominent white circle is positioned in the upper center, and a white vertical bar is located in the lower center. A speech bubble containing text is situated in the upper right quadrant.

A full life for
everyone affected
by epilepsy



More than half a million people in the UK have epilepsy. That is around 1 in 100 people

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Click on a page number
to go straight to the text.

You can also click through
highlighted text in the review
to find out more from our website.

www.epilepsysociety.org.uk

The voices of people affected by epilepsy have been at the heart of our work in 2011. With our new working name Epilepsy Society we connected with more people than ever before through our website, forum, videos, app, Facebook and Twitter, and thousands more rang our helpline or used our information resources. On top of this, we opened a new state-of-the-art care home and began work on our much awaited Epilepsy Society Research Centre. What a year!



And there's more to come. Our Targeting Seizures campaign and our medical research are setting out to make a sea change in seizure control. We are also forging new partnerships with key organisations in order to make a real difference to NHS epilepsy services.

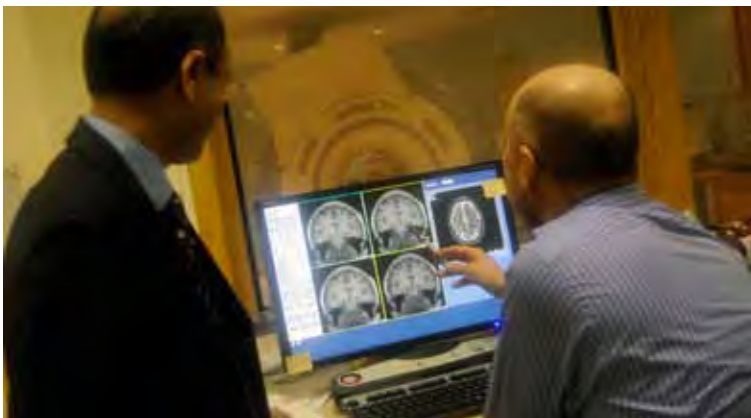
After a long time of campaigning with central government to argue that NHS epilepsy services need urgent improvement, there seem to be some real opportunities. You may or may not like the changes to the NHS, but moving decision-making to a local level and focusing on outcomes for patients may help us make a difference on the ground.

Of course money is the thing that is making the new local NHS commissioning groups sit up and listen! Luckily for us, improving epilepsy services will help them save money. Better local epilepsy services could help get seizures under control so there are fewer expensive hospital admissions and stays. We've been saying this for a long time. But when you put a cost on it to a local commissioning group (and that cost might be millions of pounds), their minds suddenly become focused.

We have become affiliate members of Neurological Commissioning Support (NCS) and are working with them and local people affected by epilepsy to audit and improve local services. This is just one of the ways in which we want to work with you to make a real difference to your seizure control.

All in order to deliver on our vision "a full life for everyone affected by epilepsy". Thank you for being part of it.

Graham Faulkner
Chief Executive, Epilepsy Society



Clockwise from top: fundraising skydivers; Chalfont Centre resident Roger in party mood; we've gone purple; fundraising dinner at BAFTA; Professors John Duncan and Sanjay Sisodiya analysing brain scans; staff at Epilepsy Society; one of our many Epilepsy Society champions.

Our regional services – formerly epilepsy information network – started as a service delivering information but now volunteers give talks and attend events to ensure epilepsy is kept on local agendas. Our epilepsy information service department has been busy updating leaflets and factsheets and our learning disability and mood resource *Epilepsy – how I feel* was highly commended by the British Medical Association. We have also produced a major report focusing on carers of people with epilepsy.



By popular demand we developed our epilepsy iPhone app for the android market and launched it during National Epilepsy Week 2011. This means that 63 per cent of smartphone users have access to this resource.

Our android app was developed with the help of a couple of volunteers who just happen to be technology experts. It now links to a comprehensive online seizure diary where seizures and events leading up to seizures can be recorded and saved for future discussion at medical consultations. And a step-by-step guide to first aid and the recovery position means it has wide appeal.

The app has featured on *BBC World News* and the Beeb's technology programme *Click*. It has now been downloaded more than 3,000 times, with a similar number installing the iPhone app.

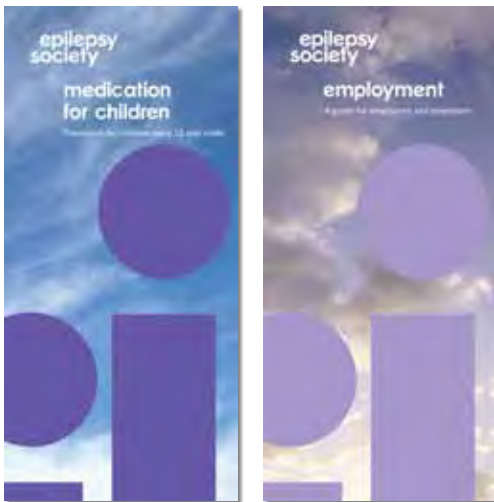
And we have a guide to the app on our YouTube channel at www.youtube.com/epilepsysociety

Ben O' Keefe
Epilepsy Information Services



You can download our epilepsy app by scanning the QR code.

We distributed more than half a million leaflets and factsheets and quarter of a million people searched for information on line.



Our epilepsy app has been downloaded more than 6,000 times by android and iPhone users.

‘Hey dude, really like the app. Can I tell patients to download?’

Text message to Epilepsy Society’s medical director, Professor John Duncan, from the secretary of the EEG telemetry unit.

Top: our new-style exhibition stand. **Below:** the UK’s first app for epilepsy.

researches

This year has seen us cut the turf for our long awaited Epilepsy Society Research Centre – an exciting project which will enable us to further develop our already extensive programme of groundbreaking research at the Chalfont Centre in Buckinghamshire. You can follow the centre's development at www.epilepsysociety.org.uk/epilepsysocietyresearchcentre



Understanding how an individual's genetic make-up can affect their risk of developing epilepsy, the consequences and their response to treatment are central to our research at Epilepsy Society.

As part of an international collaboration we have been able to identify a [genetic variant](#) which is linked to both mild and severe reactions to one of the most commonly prescribed drugs, carbamazepine.

We have highlighted the positive impact that a correct diagnosis of [Dravet syndrome](#) can have on adults with this difficult-to-control form of epilepsy – leading to better seizure control, improved quality of life and cognitive performance.

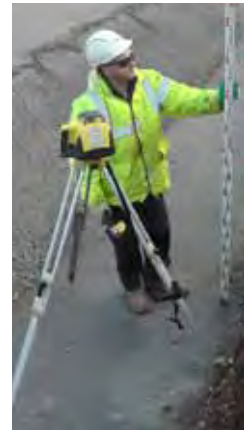
We have found that deletions or [duplications](#) of genetic material may be associated with various epilepsies and now hope to identify the functional consequences of these abnormalities so that we can better understand the cause of the epilepsy and how to treat it.

And using [Ocular Coherence Tomography](#) (OCT) – one of the most advanced scanning tools for measuring the retinal fibres at the back of the eye – our preliminary findings have shown for the first time that people with epilepsy have thinner retinal nerve fibres than those without the condition. More research is needed but it could be that the retina is a mirror of changes in the brain. »

Professor Sanjay Sisodiya
Epilepsy Society

'Although the proportion of epilepsy explained by this deletion is relatively small – about half a per cent – that still translates to possibly 300,000 cases worldwide.'

Professor Sanjay Sisodiya on the discovery of a microdeletion on chromosome 16.



This year our research department has published 143 papers in scientific and medical journals, 21 book chapters and two books.



'The eye is really turning out to be a window on the brain... OCT may provide an easy and reliable way of monitoring the brain.'

Professor Sanjay Sisodiya on OCT and retinal nerve fibres.

Clockwise from top: artist's impression of our new Epilepsy Society Research Centre; measured approach to the new building; Professor John Duncan leads research discussion; OCT measuring the eye; analysing blood samples.

campaigns

In 2011 we made significant strides on a number of fronts. Our University Challenge campaign resources were used by universities, colleges and sixth forms across the UK. Many people with severe epilepsy are being assessed 'fit for work' when they are not and we encouraged you to challenge your benefits assessments. We also successfully campaigned for the Government to stop plans to remove the mobility allowance for people in care with disabling epilepsy. And we are working with you to build a platform for our Targeting Seizures campaign.



‘ The voice of people affected by epilepsy is often missed. We are listening. We want to make sure everybody else does too and that people affected by epilepsy feel comfortable with sharing their story. Having a voice is sometimes easier said than done when confronted with a condition that can seem mysterious and is often misunderstood.

We are trying to break down the barriers and foster understanding. In our Make the Connection survey, people affected by epilepsy talked openly about feelings, friendship and misunderstandings that come about when you tell someone that you're affected by epilepsy. We are hoping this report will really get people talking about the subtler, more invisible side of living with epilepsy.

A major report on carers also voiced the feelings and experiences of those closest to people with epilepsy, recognising that the condition can often have a major impact on their lives. ’

Jenny Rush, Head of campaigns, communications and information services

'The decision to retain the mobility element of the Disability Living Allowance is an excellent result for those with complex epilepsy in residential care.'

Graham Faulkner, Chief Executive, Epilepsy Society



We promoted our University Challenge campaign on Facebook using targeted adverts on a limited budget. The advert was seen by 324,656 Facebook users.

'Carers are strong and resourceful people who are very skilled at what they do. However, caring can dominate their life and leave little time for their interests.'

Healthcare professional talking about how caring affects carers.

Top: residents put the case against cutting the mobility allowance to Lord Low. **Centre:** our University Challenge comic strip. **Below:** Laura Sandys MP – a voice for epilepsy in parliament; connecting with carers survey.

connects

Reaching out to one another and making that vital connection is fundamental to everything we do at Epilepsy Society, whether it is through sharing information, supporting one another, fundraising or volunteering. Digital media means we really are part of a vibrant global world that is instant and accessible and it's helping to change the face of epilepsy.



‘ If there’s one word that sums up the past year for me, it’s “connecting”. In reaching out to support people with epilepsy and their families throughout the country we have now made it easier for people to connect with each other and with us.

Our name change to Epilepsy Society in January 2011 was an important step. Visitors to our website have increased by as many as 10,000 a month, while the fast moving world of digital media means we have developed a nationwide network of volunteers, fundraisers and users of our services through our forum, Facebook and Twitter sites.

We have also produced helpful, informative and entertaining videos on YouTube, and the development of our app for use via Smartphones has been a first in the UK for epilepsy.

But no matter how fast the world of communication is changing, we are still always pleased to receive letters and cards from you through the post. We were particularly pleased to hear from supporter Patsy Cannon in Oxfordshire who sent us our first card to mark our 120th birthday next year. We have made Patsy an Epilepsy Society champion.

We estimate that our 250 regular volunteers are worth around £320,000 a year to us – but the real value is the friendly face at the point of contact, whether in hospital clinics, delivering our schools awareness programme, or helping in the gardens at our Chalfont Centre, Buckinghamshire. ’

Bridget Gardiner
Director of fundraising and marketing



You can download our epilepsy app by scanning the QR code.

We have 8,300 forum users, 4,800 Facebook likes and more than 1,000 Twitter followers.



'I have just started following Epilepsy Society on Twitter. It's great to see how many people there are who really understand about epilepsy.'

Bex Rumble, Banbury



Clockwise from top: Epilepsy Society champion Patsy Cannon; our supporter newsletter *response*; volunteers from Centrica helping with our horticulture project; supporters making the connection.

'The forum is an amazing place – you really feel part of a family. There is such incredible warmth and support from our members.'

Ruth de Grey
forum moderator

educates

Our schools awareness programmes, information stands and training for professionals are a bedrock of our work to raise the profile of epilepsy. But we also look for new ways to get epilepsy onto the public platform. This year, for the first time, our annual conference went interactive with delegates sharing their own experiences of living with epilepsy. A moving and memorable experience. We were also pleased to advise on the storylines of two TV programmes featuring epilepsy – ITV’s *Coronation Street* and Channel 4’s drama *The Promise*.



Education and awareness raising are a central focus at Epilepsy Society and we welcome the chance to work with young people nationwide. Our schools awareness programmes give us a fantastic opportunity to help break down the myths and stigma that can still surround epilepsy. Often we go into schools where a pupil with epilepsy may be having trouble coping with their seizures or may be experiencing friendship problems – even in today’s more enlightened times bullying and isolation exist.

The incredible reception we receive and the positive attitude and response of pupils underline the importance of sharing information. This year our programme has been presented 73 times in 18 schools reaching nearly 3,000 pupils and more than 200 staff. Since the programme began, we have reached 17,000 pupils. We have made two schools – Chalfont Community College in Buckinghamshire and Springfield School in Portsmouth – Epilepsy Society Champions to mark their commitment over five years to raising awareness of epilepsy and reducing stigma in the classroom.

And this year we have extended our programmes further by making them available online for use with pupils aged between seven and nine. There is a downloadable lesson plan about epilepsy for teachers. You can find it at www.epilepsysociety.org.uk/schools

Elaine Falkner
Community outreach manager



epilepsysociety epilepsy society
 Now time to munch, watch some 'Your Say' speakers, find out about our info services, watch a demo of our app & get on camera!
 #conference2011
 15 Oct

epilepsysociety epilepsy society
 Now a great talk from Frances Gibbon, with video of some young people's first-hand #epilepsy experiences #conference2011
 15 Oct.

'... our hard-working Swindon volunteer gave a talk to his local blind persons' support group following his schools awareness programme training. He was able to adapt his presentation for the 13 adults with little or no sight ...'

Brenda Willis, regional manager south west

'In KS3 we have several pupils with epilepsy but few incidents of bullying because this programme has been running for a few years.'

Epilepsy Society schools awareness evaluation



Clockwise from top: Twitter feed from our annual conference; our magazine *Epilepsy Review*; school pupils learn about epilepsy; Springfield School is made an Epilepsy Society champion.

diagnoses

The rate of misdiagnosis in epilepsy is high. As many as one in five people are taking anti-epileptic drugs when the cause of their seizures is not epilepsy. At the same time, people with hard-to-treat seizures are waiting as long as 20 years before they are considered for brain surgery. Both these facts underline the importance of new and improved diagnostic tests at our Sir William Gowers Assessment Centre in Buckinghamshire which are helping us make real changes to people's lives.



Every day we see people at [Gowers](#) for whom uncontrolled seizures have a huge impact on their lives. When a seizure is generated in the brain it causes a temporary disturbance to that person's ability to function but the disturbance to their every day life can be much longer lasting. It may affect their ability to work, enjoy a full social life, drive and even support a family.

Which is why a new generation of diagnostic tests now in clinical use is so important, offering the possibility of better treatment for those whose seizures are hard to control and helping us to reach a correct diagnosis for those whose seizures are non-epileptic.

Sophisticated diagnostic testing is enabling us to see deeper into the brain and to unravel the complex genetic factors that may predispose an individual to epilepsy and influence their response to treatment.

Advances in structural and functional imaging of the brain are helping us reveal the underlying causes of seizures in patients whose MRI scans have previously proved inconclusive. They are also allowing us to predict more accurately and minimise the likely impact of surgery on memory, language and vision.

Alongside this our recent study has shown that 10 years after epilepsy surgery, around half of patients remain seizure free. Surgery is not suitable for everyone of course – but for those with focal epilepsy where the source of the seizure can be identified, it should be considered now, not in 20 years time.

Now is the time to ask for a medical review of your epilepsy. »

Professor John Duncan
Medical Director, Epilepsy Society



More than 9,000 blood tests have been analysed in our Therapeutic Drug Monitoring unit since January.



'Gowers was a turning point in my life. The care and attention that I received went way beyond anything I could have imagined. The standard of medical care is absolutely excellent but the centre also offers so much more. At Gowers I got back my self-motivation to get better.'

Karen Arnett, a patient at our Sir William Gowers Assessment Centre.

Nearly 3,000 outpatients have been seen this year by our team of doctors.



1,000 patients have been assessed at our Gowers Centre.

Clockwise from top: Professor John Duncan takes time out in Gowers assessment unit with former brain surgery patient Elyse Westrip; on the ward; a welcome reception from administrator Suzanne Gross; patients and staff outside Gowers.

enables

Epilepsy Society provides a support package tailored to people with complex epilepsy. Our wide range of services – from medical to emotional support – are provided by a multi-disciplinary team of experts at our residential care homes in Buckinghamshire. We are committed to ensuring a ‘nothing about me, without me’ approach to care – which is at the heart of a new ‘bill of rights’ created by residents. Individualised care and empowerment are central to our new home, Micholls House, which was opened by our president Countess Howe in September.



‘ When Jamie left school at 18 there were only four places in the south east which could cater for his complex needs. From those we chose Hastings as it was the closest to our Buckinghamshire home but meant a 160-mile round trip to visit Jamie.

Then I read on the internet about Epilepsy Society’s new care home, Russell House which opened in 2009. I got in touch immediately but unfortunately the house was full. When I heard about Micholls House I put Jamie’s name down for a place straight away.

Obviously we’ve had a long transition period but I was delighted when Jamie moved in last July. Now he’s only six miles down the road and all the family can pop in to see him whenever we like. He’s so settled and the staff are great. They’ve got to know Jamie really quickly and whenever we visit he’s so happy. ’

Lori

Jamie’s mum – Jamie lives in Micholls House



‘As soon as David came to Queen Elizabeth House, he just blossomed. Best of all he is leading a normal life with friends and activities, personal goals and just fantastic staff to look after him.’

Edna, David’s mum



Clockwise from top: Micholls House; residents present their bill of rights with Eileen Springford, chairman of our trustees and Cheryl Gillan MP; Resident David with mum Edna; resident Jamie with mum Lori; our president Countess Howe plants a tree at Micholls House.

listens

Epilepsy Society's confidential helpline provides a listening ear to around 5,000 callers each year. It's a unique service providing information, time to talk and in depth emotional support.

Our helpline is caller led, and for many this is the most important aspect of the service giving people time and space to make informed choices. Many callers say they feel rushed by their doctor, and the helpline offers a safe space for them to unpack their concerns.



“ A recent evaluation of our helpline has given us further insight into the way the service is used and an opportunity to consider future strategies to deal with call demand and service enhancements.

The good news is that 99 per cent of callers felt they had been listened to, their needs understood and any information they were given was relevant to their situation. A small percentage of callers were health professionals, and many respondents were newly diagnosed.

Around 70 per cent were first time callers – a growth of more than 200 per cent since the last evaluation in 2007.

Around 16 per cent of people had called more than twice, showing they felt welcomed by the service and that it is of ongoing value to them. The helpline team has noticed an increasing number of extremely isolated callers for whom the helpline is a lifeline.

The majority of callers, 93 per cent, said their concerns were recognised and 88 per cent felt they got what they wanted from the service. We are glad people get a lot from their call. ”

Christine Brock
Helpline manager

**epilepsy
society
helpline**

01494 601400

Monday to Friday 10am–4pm
(national call rate)

'Reassured and relieved to know it was confidential. So lovely to have a professional but friendly person to talk to. It helped me to open up and really talk about what I wanted to know. Exceeded my expectations. Thank you.'

'I am so impressed with the service and not so scared now to deal with the issues currently facing me as a parent with a child who has seizures.'

'I felt understood for once in my life.'

'It was nice to talk to someone who listens and cares.'

'It was extremely helpful and gave me the courage to continue.'

'The lady on the end of the phone gave a lot of support and time to explain things.'



Our helpline takes around 100 calls per week from people wanting to talk about diagnosis, medication, safety, first aid, risk and isolation... or simply to talk.

fundraises

There's no escaping the fact that 2011 has been a tough year financially for everyone, yet still our fantastic supporters never let us down with their fundraising. From individuals to trusts, companies and organisations, your generosity knows no bounds. We are always touched by your tremendous support which enables us to continue providing services such as our confidential helpline, and to undertake pioneering research which will make a real impact on the lives of those with epilepsy.



Just weeks after recovering from brain surgery, 20-year-old Jasmine Smith raised a fantastic £4,440 for Epilepsy Society with a special 'Jasmine Day'. A YouTube video about Jasmine's story also featured in our Christmas appeal and was watched by over 500 people.

Thirty-five runners pounded the streets of London in the marathon to support people with epilepsy. Among them was the amazing Sam Robson who completed the race then ran home to St Ives in Cambridgeshire. Sam ran 120 miles and raised more than £3,000.

A team of 12 daredevils, including Wendy Kay, skydived to raise nearly £10,000. Robin Knight took part in the world's largest 24-hour mountain bike race dressed in a sumo suit, while Paul Klimczak trekked to Everest Base Camp.

Our supporters also remembered us at celebrations such as weddings, anniversaries and birthdays when they asked for donations instead of gifts. And we would like to mention all those who chose to support us with gifts in their wills.

The list of our supporters is endless and includes everyone who contributed to our spring appeal, annual draw and Christmas appeal. And of course a big thanks to the trusts and funds who have supported us and to our corporate partners including UCB Pharma, GlaxoSmithKline, Eisai, GE Healthcare, Special Products, Barnett Waddingham and Medtronic. We'd like to thank you all.

Eve Robinson
Fundraising development manager



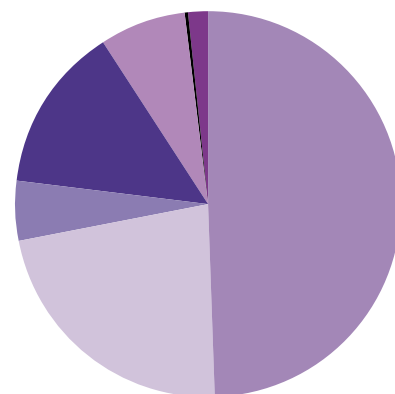
Clockwise from top:
Everest climber Paul Klimczak; sumo man Robin Knight; Jasmine Smith and Professor John Duncan; Team UCB Pharma at their charity auction; marathon man Sam Robson.

Summary of financial information for year ending 31 March 2011

Total income

£000s

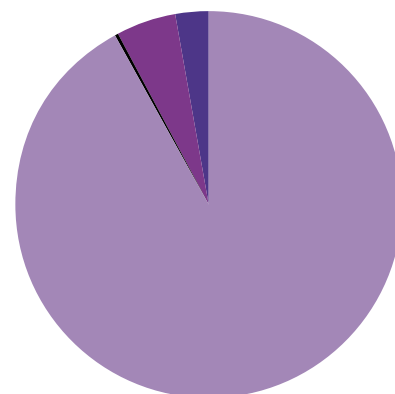
■ Residential and nursing care services	9,362
■ Donations, legacies, grants and events	4,236
■ Rents and other activities for generating funds	971
■ Medical services	2,612
■ Other charitable activities	1,368
■ Investment income	33
■ Gain on sale of assets	292
Total incoming resources	18,874



Total expenditure

£000s

■ Direct charitable expenditure	16,109
■ Governance support cost	36
■ Fundraising and publicity	879
■ Cost of trading and other costs	473
Total resources expended	17,497



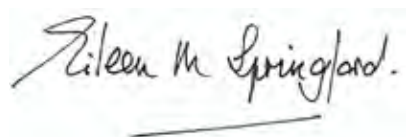
Summary of Epilepsy Society's balance sheet at 31 March 2011

£000s

Fixed assets	30,015
Current assets	3,634
Creditors: amounts falling due within one year	2,127
Net current assets	1,507
Creditors: amount falling due after one year	7,471
Pension scheme deficit	2,616
Net assets	21,435

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.



E M Springford
Chairman of the trustees
28 July 2011

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 10am to 4pm

Confidential. National call rate.

Information and emotional support.

Epilepsy Society

Chesham Lane, Chalfont St Peter, Bucks SL9 0RJ

01494 601 300

Epilepsy Society is the working name of The National Society for Epilepsy,
registered charity no. 206186

