
DECODING EPILEPSY

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**epilepsy
society**



RESEARCH

Epilepsy: a new era

This special edition of *Epilepsy Review* is dedicated to our research at Epilepsy Society Research Centre. Here, our medical director Professor Ley Sander explains how we are at an exciting moment in the history of epilepsy with modern advances leading to improvements in our understanding and treatment of epilepsy.

When we opened our doors at Epilepsy Society Research Centre less than two years ago, we asked you to tell us your hopes for the future. Not surprisingly many of you expressed a wish for a world without epilepsy and this is the driving force behind our research. People affected by epilepsy are the main focus of our priorities.

When it comes to research, we tend to talk in terms of large-scale global studies, anonymised statistics, double-blind randomised controlled trials, cohorts of people with similar seizure types or control groups. We could easily become distant from the reality of epilepsy and the impact it has on the individual, their friends and families.

‘There are positive signs that epilepsy will disappear as a description of a disease.’

Except that our research centre is integrated with our medical centre and magnetic resonance imaging (MRI) unit here at the Chalfont Centre in Buckinghamshire. Our researchers – some of the brightest minds from across the globe – see patients on a daily basis. They see for themselves the toll that epilepsy can impose on people – the unpredictability of seizures, the side effects from medication, the memory loss, anxiety, depression and the stigma which is still a constant in many people’s lives. It adds a very real urgency to our work.

So, how far have we come? Cautiously, I can say there is real hope that we are beginning to witness an exciting moment in the history of epilepsy. For the first time we are starting to see a shift from a model of treatment based on experience and observation to one based on a fuller knowledge of the individual’s genetic profile and on a better understanding

of the way in which different anti-epileptic medications work.

The realisation that epilepsy is always a genetic condition, in which a lower seizure threshold is part of a person’s genetic blueprint but not necessarily inherited, is leading to a major improvement in the understanding and treatment of epilepsy. Our better understanding of the way different drugs work is helping to bring targeted, disease-modifying therapies to the forefront.

But we are not there yet. A thorough understanding of the brain, its diseases and the effects of drugs on neurons is still very much a work in progress. And of course we couldn’t do it without the thousands of our patients who willingly sign up for our research projects, as determined as we are to unravel the complexities of epilepsy.

Our research is following three main directions. Firstly we want to work out the risks of a person developing

Our Epilepsy Research Group



Epilepsy Society is part of a unique arrangement with University College London and the National Hospital for Neurology and Neurosurgery. This ensures academic and clinical excellence, patient input and relevance of our medical research. We are also a World Health Organisation (WHO) Centre of Excellence.

In the last year we were nominated as the top epilepsy research centre in the world by Expertscape, and Epilepsy Society’s medical director Professor Ley Sander was ranked as the world’s leading expert on epilepsy.

Research in this magazine looks at work of the whole research group. Epilepsy Society does not fund all this research.



Piecing together the jigsaw of epilepsy: Professor Ley Sander with Hughlings Jackson, one of the founding fathers of Epilepsy Society.

epilepsy, clarify the underlying causes and identify factors that will predict the long-term outcome for people with the condition. With advances in the understanding of the genetic contribution to the risk of epilepsy, this is an area in which we expect significant developments.

Recent technological advances have accelerated our progress. Sophisticated neuro-imaging software is helping us to identify the focal point of seizures in otherwise normal looking brains. New imaging techniques such as optical coherence tomography (OCT) and 3D facial photography are helping to identify patterns too subtle for the naked eye to register and helping us to classify more precisely some epilepsy characteristics or syndromes.

Our second priority is to improve the therapeutic options available in epilepsy as well as discovering new and innovative therapies. At the moment, prescribing anti-epileptic medication is still very much a matter of trial and error. There is little we can do to predict who will respond to different medications and who will develop unacceptable side effects. I would hope that in the not-too-distant future our progress in genomic medicine will allow tailored treatment for all people with epilepsy, based on their genetic make-up.

Our third priority is to reduce the burden that epilepsy can impose on people, a burden which we know can often have a greater impact on quality of life than the seizures themselves.

In 1873, Hughlings Jackson, one of the founding fathers of Epilepsy Society, defined epilepsy as 'occasional, sudden, excessive, rapid, and local discharge of grey matter.' In the 19th century this was a major milestone in the understanding of the condition.

Today there are positive signs that epilepsy will disappear as a description of a disease and be replaced by the knowledge that it is a collection of rare diseases with a common feature: a predisposition to epileptic seizures.

The epilepsies are falling apart. We are working on it. To all of you who contribute to our research, a huge thank you.

*Professor Ley Sander
Medical director, Epilepsy Society*

Epilepsy Review Research Special



FRONT COVER

Magic Forest, 2002 Image courtesy of Andrew Carnegie andGV Art Gallery London www.gvart.co.uk

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Research news

From the experts

GENETICS

Genes identified for common epilepsies

Working with the International League Against Epilepsy Consortium on Complex Epilepsy, we have identified two genes which may have a broader role to play in common epilepsies than originally thought. SCN1A – the gene associated with Dravet syndrome – and a second gene that encodes for the protein protocadherin, may increase the risk of developing epilepsy. Read more about our genetic research on page 6.

SEIZURES

Moon watch

Did you know that more people search for epilepsy information on the internet when there is a full moon? We analysed online epilepsy searches worldwide between 2005 and 2012 and found a small but noticeable positive association between a full moon and increased online epilepsy searches. This could be a result of increased sleeplessness during periods of a full moon, but suggests the need for further studies.

ALTERNATIVE THERAPIES

Light fantastic

Bright light therapy has been shown to significantly reduce symptoms of anxiety and depression in people with focal epilepsy. Fifty eight people took part in a trial led by Epilepsy Society neuropsychologist Dr Sallie Baxendale. Anxiety and depression scores were significantly lower following light therapy although researchers observed no noticeable difference between those receiving high and low intensity treatment. Further research is required.

ALTERNATIVE THERAPIES

Ketogenic diet trial in adults

In a small study of the ketogenic diet, popular as a therapy for children with epilepsy, we found that 39 per cent of adults on the high-fat, low-carbohydrate diet, showed a 50 per cent or more decrease in seizure frequency. The study was carried out by scientists in London and the Netherlands and three leading epilepsy charities. A controlled study is now needed. Read more about the ketogenic diet on page 17. www.epilepsysociety.org.uk/ketogenic-diet

AEDS

No more needles

There is good news for people with a fear of needles and for children, the elderly and those who don't like giving blood. Scientists at our therapeutic drug monitoring (TDM) unit, led by Professor Philip Patsalos, have found that monitoring drug levels in saliva can offer a convenient and painless alternative to taking blood samples. Drug monitoring is used to help optimise the level of epilepsy drugs on an individual basis.

AEDS

Review of once-a-day drug

Perampanel (Fycompa), the latest anti-epileptic drug to be licensed as an add-on treatment for partial onset epilepsy, has been welcomed as an alternative approach in the management of seizures. Professor Philip Patsalos, head of our TDM unit, and researchers from Oxford University Hospitals Trust, carried out a review of the once-a-day drug. They said it had the potential to have a significant impact on the long-term outcome for people with the condition.

Remembering Jamie



James Lewis was about to start studying for a BA in arts when he lost his life to SUDEP – Sudden Unexpected Death in Epilepsy. He was 23 and is pictured here with his last painting. A foundation, set up in his name by his family, now funds research into epilepsy.

James' family share their story on page 15

DIET

Omega-3 fatty acids and seizures

Could omega-3 fatty acids help control seizures? We carried out a small open-label study looking at the effects of the omega-3 fatty acid EPA (eicosapentaenoic acid) on ten people with difficult-to-treat epilepsy over a three-month period. Results showed six people had fewer seizures and one had reduced seizure activity. The study involved a small group of people and no control group. More studies are needed.

ALTERNATIVE THERAPIES

Rescue treatment

We are involved in developing more practical alternatives to rectal diazepam for prolonged seizures, including formulations of buccal midazolam and lorazepam as a spray and powder.

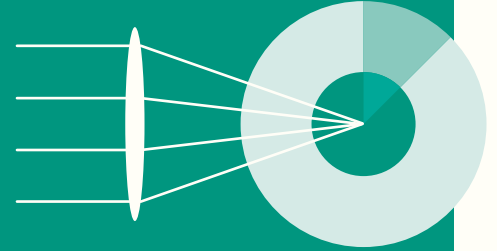
AEDS

Understanding newer treatments

During the last seven years, six new anti-epileptic drugs have been licensed for the treatment of epilepsy. Scientists at our therapeutic drug monitoring (TDM) unit are looking at the way these drugs are absorbed, distributed and eliminated from the body. This will help us to better understand at which stage these drugs should be prescribed in the treatment of an individual.

Research in numbers

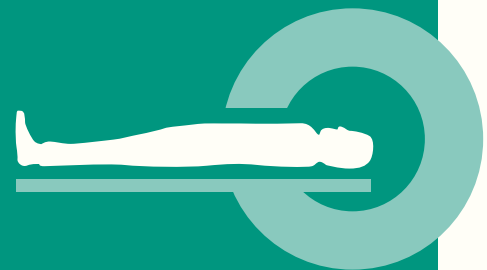
196 people scanned using optical coherence tomography



80 people have been scanned using our new transcranial magnetic stimulation (TMS)



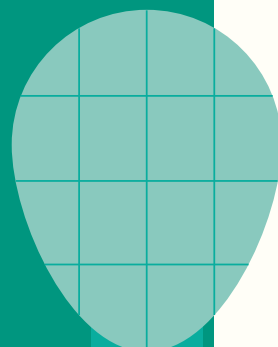
170 MRI scans carried out for research*



115 3D face scans carried out to evaluate genetic contribution to epilepsy

Figures relate to October 2013 – September 2014.

*Our MRI scanner was updated in November 2013. Research scans resumed in February 2014.



Decoding epilepsy

Genetics can tell us more about epilepsy in a single test than any other source. Professor Sanjay Sisodiya, lead geneticist at Epilepsy Society, explains how genetics is shining a light on our understanding of the causes of epilepsy and how that knowledge is beginning to help make a difference to those whose lives are dominated by seizures.



For the last 15 years I have been seeing a patient in my clinic for whom I have been unable to provide any explanation as to the cause of his seizures. Richard – not his real name – first started coming to see me at the age of 21, and throughout the years the diagnosis on his fairly substantial set of medical notes has read ‘refractory epilepsy with mild learning disabilities.’ I could offer his parents no fuller an explanation.

We had tried to identify the underlying genetic cause of Richard’s

epilepsy using a specific DNA test called an array Comparative Genomic Hybridisation (aCGH) test. This looks for parts of a person’s hereditary material or genome that might be missing or which might have been duplicated, causing epilepsy and other conditions such as autism or learning disabilities.

The human genome is made up of vast stretches of DNA comprising three billion letters, and an aCGH test allows us to read 200,000 letters at a time. But in Richard’s case, this did not give us the answers we needed. We had to think again.

We turned instead to the latest, most advanced form of DNA sequencing – next generation sequencing. We chose to look at Richard’s exome. This involves the small percentage of a person’s genetic make-up – around 10 million letters – carrying the most important sequences of DNA that direct the body to make proteins essential for it to function properly.

We sequenced the exome of not

just Richard, but his parents as well. This trio strategy is used when we think that a son or daughter may have a ‘de novo’ or new genetic mutation that has not been inherited from either parent.

Although we will soon begin to carry out trio strategy sequencing here at the Epilepsy Society Research Centre, Richard and his parents’ DNA was outsourced for sequencing. And the results that came back were exciting. We found a small number of changes in a single letter in Richard’s DNA which did not also appear on the DNA of either of his parents.

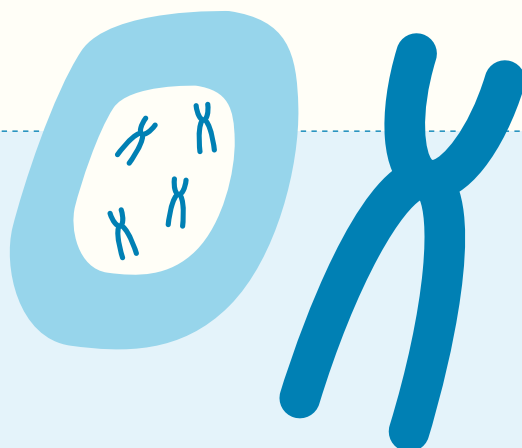
This discovery was exciting but small changes in a single patient cannot be given too much significance. It was only when I shared our findings with long-standing research collaborators around the world that we discovered five other people with the same genetic mutation and the same characteristics.

Finally, one Friday afternoon, I was able to phone Richard’s mum and tell her that we had found what was

Genetics

The **cell** is the basic unit of every organ or system in the body. Our bodies are made up of millions of tiny cells.

The **nucleus** is the control centre of our cells where chromosomes are stored.



We have 23 pairs of **chromosomes** each composed of two long, thin strands of deoxyribonucleic acid, known as DNA.

Our **DNA** contains our hereditary genetic material. If stretched out, the DNA from one human cell measures 6ft or 1.8m.

probably the cause of Richard's epilepsy. Finally I could tell her that the seizures which have dominated Richard's life were the result of a single letter that was changed in a specific gene.

Because of the location of the mutation, this also meant that there were some particular epilepsy drugs that Richard could try which could potentially change some of the effects of the faulty gene. It wouldn't be a cure – we are not at the point of gene therapy, that is still a long way off – but it could be an improvement. This wouldn't be the case with all genetic mutations but we were quietly confident with Richard.

The story of Richard and his family illustrates where we are today with unravelling the underlying genetic causes of epilepsy. Genetics can tell us more about epilepsy in a single test than any other source.

In the last few years the number of genes that we have been able to identify as being responsible for different forms of epilepsy has gone from a handful to hundreds.

We are recognising epilepsy syndromes, defining them genetically and we are beginning to understand them biologically. We are moving from discovering genes that are responsible for epilepsy to applying that knowledge in clinical practice. And collaboration on a world-wide scale is very helpful in furthering our understanding.

At the moment our focus is still looking at the extreme forms of epilepsy characterised by uncontrolled seizures and difficulties such as learning disabilities. The reason for this is two-fold. Firstly, in severe forms of

epilepsy which give rise to similar characteristics it can be easier to pinpoint the missing part of the genome which is causing the mal-functioning genes. In less severe epilepsies, where there are no similar characteristics, it can be far more challenging to pick out the genetic variants which are causing the seizures.

'Finally, one Friday afternoon, I was able to phone Richard's mum and tell her what was probably the cause of his epilepsy.'

Secondly, DNA sequencing costs between £600-£1,000 per test so we are only able to get funding for those most severely affected. This is exactly the same scenario that we faced 20 years ago when we first installed an MRI scanner here at the Chalfont Centre in Buckinghamshire. The cost of an MRI scan meant that only the most severe cases could be scanned. Today, MRI scans are a routine form of investigation for everyone with epilepsy and within two to three years we expect DNA sequencing to become a routine part of diagnosis, too.

But genetically defining the epilepsy syndromes is providing a good paradigm or model for moving ahead with our understanding of the more common epilepsies. We know that by recognising a recurrent clinical

picture occurring in several people, we can then start to explore what is happening both genetically and biologically.

Once we have established a faulty gene, we can recreate a model of that gene in a dish and try to get a better understanding of how it functions and how it responds to different medications.

A recent exome sequencing study enabled us to identify the genetic cause of DOORS syndrome, a rare condition characterised by disabilities including deafness, intellectual impairment and seizures. Having identified the mutation, the next step is to find out which is the right drug for people with the syndrome.

Alongside exome sequencing, we are also using 3D face imaging to explore the link between face shape and genetic variations which can lead to epilepsy. Our research has shown that facial shapes are as varied as the underlying genetic structural variations but there can be subtle changes in the face in particular types of epilepsy. At the moment we are only using this as a research tool but we hope that in the future it will become an important tool in the diagnosis of particular epilepsy syndromes.

I hope that genetics will help us cast a light on all aspects of epilepsy including the cause, a person's susceptibility, their history, seizure type, treatment response, outcome and accompanying conditions.



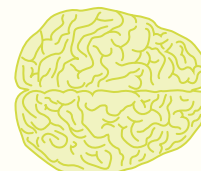
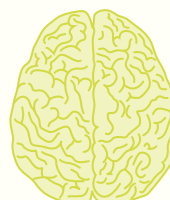
Our **genome** is made up of 3 billion letters arranged in pairs along our DNA. There are 4 base letters: cytosine (C), guanine (G), thymine (T) and adenine (A).

The **exome** consists of about 10 million letters which produce proteins which in turn enable the body to function properly. This is the focus of our research.

A **mutation** is a rare change in a normal sequence that may alter the function of a protein and can lead to disease.



Leading the field in epilepsy:
Professor Sanjay Sisodiya and
his team of genetics researchers.



Umair Chaudhary

The corpus callosum which connects the right and left sides of the brain. Good communication skills are important for success.

He Ci

The anterior commissure which works with the posterior commissure to link the two cerebral hemispheres of the brain. Also the thalamus between the cerebral cortex and the midbrain – it is a switchboard of information.

Mark Nowell

The amygdala – this is where abnormalities often cause epilepsy. Also the premotor area – as a neurosurgeon it is important to learn complex tasks until they become second nature. The premotor area plays an important role in this.

Roman Rodionov

The precuneus – it is one of the most connected processing hubs in the brain, but also the limbic system, responsible for emotions including love.

We asked our researchers to name their favourite parts of the brain in terms of research.

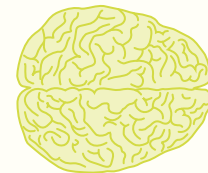
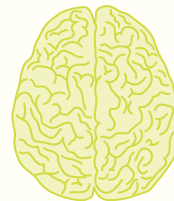
Meet the team



Left to right: Costin Leu, Joseph Willis, Sanjay Sisodiya, Zuzanna Michalak, Andreja Avbersek, Bridget Maher, Ana Paula Bartmann, William Stern.



Benchmark of success:
researchers from our
neuroimaging team.



Niraj Sharma

The piriform cortex – exciting new research suggests this may be the area involved in seizure activity.

Also the prefrontal cortex – damage to this area of the brain can reduce a person's capacity to manage their impulsive response to a situation and can cause depression and schizophrenia.

Ana Paula Bartmann

The visual pathway – it is so complex and can be affected by epilepsy and other diseases in a very intriguing way. Also mirror neurons – I like the concept of neurons dedicated either to identify emotions in others and develop empathy, or just to teach us how to move like others (perhaps if I see enough people dancing, I'll be able to dance myself one day).

William Stern

The motor cortex – when I stimulate this part of the brain in a patient using TMS (see page 17), their hand twitches and I can record that. Also the visual cortex which analyses things we see. It also seems that visually impaired people use their visual cortex for similar tasks to everyone else, but using information from touch and hearing instead of vision. It's a great example of how complex and adaptable our brains can be.

Peter Gilford

The temporal lobe, because it deals with déjà vu.



Back row, left to right: Roman Rodionov, Umair Chaudhary, Peter Gilford, Mark Nowell
Front row left to right: Niraj Sharma, Britta Wandschneider, Irene Pappalardo, Gloria G Gonzalez, Louis Lemieux, He Ci.

It is more than 100 years since the first anti-epileptic drug (AED) revolutionised the treatment of people with epilepsy. Today, our choice of drugs has increased dramatically. While we know that one size does not fit all, we still do not know why epilepsy in some people remains drug resistant, while others experience unpredictable side effects. Looking at the underlying causes of people's responses to drugs and understanding how drugs behave on a long-term basis is a key part of our research.

There are 24 drugs licensed for epilepsy in the UK. Yet for at least 30 per cent of people with the condition, their seizures remain uncontrolled while for others there is often a delicate trade off between seizure control and side effects from their medication.

Forty-seven per cent of people will achieve seizure freedom on the first drug irrespective of the drug they are prescribed, 32 per cent after the second drug, nine per cent after the third and five per cent after subsequent drugs.

Adverse drug reactions are mostly unpredictable and are often considered more of a burden than the seizures themselves. Tiredness, weight gain, weight loss, forgetfulness, difficulties in concentration and mood swings are regularly cited as side effects of epilepsy drugs. In rare cases, certain drugs may even increase the risk of foetal malformations in the babies of women who are prescribed them during pregnancy.

Although certain drugs are more suited for specific seizure types such as focal, myoclonic or absence seizures, it can still be a matter of trial and error in getting the right drug for the right individual at the right dose. And this is where our research comes in.

At Epilepsy Society we are using both DNA sequencing and neuroimaging to try and determine why some people have a positive response to certain drugs while others experience adverse drug reactions. Our goal is to ensure that people with epilepsy receive the right medication at the right dose from the point of diagnosis. Our goal is personalised medicine for all.

Collaborating with colleagues across the world often helps us to take research forward. Working with colleagues in Liverpool and Dublin we have already shown how a person's genes can predetermine whether they are likely to have a severe adverse reaction to the anti-epileptic drug carbamazepine.

Now, in the field of genetics, we are working with researchers and scientists across Europe to try to unravel more about the relationship between drugs and genetics. In the same way that a person's genetic blueprint can determine their risk of developing epilepsy, it can also predict the way they respond to, and tolerate, different medications.

Led by Professor Sanjay Sisodiya, we are part of the European research project EpiPGX, a consortium of 15 organisations from Iceland to Italy which aims to understand why only some people can be treated successfully with anti-epileptic drugs.

Working collaboratively across such a large number of organisations enables our researchers to carry out genome-wide genetic analyses of DNA samples from more than 12,000 people across Europe, comparing hundreds of thousands of genetic variants in people with different treatment outcomes.

We are looking at several specific groups of people:

- those who respond to medication early or late
- those who are resistant to medication

AEDs and
side effects

- those who develop adverse drug reactions
- women who have babies with developmental malformations.

By comparing patients who have an adverse or good response to a particular drug, we can try to find a common genetic link between them. Ultimately, this will help us to prescribe the right medicine from the point of diagnosis without having to use the trial and error approach that can involve several different medications or combination of drugs.

Overactive protein

We are also using genetic research and advanced neuroimaging techniques to investigate the possibility that overactivity of certain proteins in the brain may be linked to drug resistance and increased seizure activity.

We have already used neuroimaging to look at the protein P-glycoprotein (Pgp) that influences the distribution, absorption and elimination of drugs in the body, possibly taking drugs away from their targeted site of action and reducing their concentration and impact.

Pgp works by pumping unwanted chemicals in the bloodstream, such as toxic substances, out of the brain. However Pgp is unable to tell the difference between harmful and helpful chemicals, seeing any foreign substance in the brain as a potential threat. This means Pgp can prevent potentially helpful drugs, including some anti-epileptic medications, from reaching the brain.

Using a three dimensional scanning technique – Positron Emission Tomography (PET) – we have shown that there is a clear link between over activity of the P-glycoprotein in some regions of the brain and temporal lobe epilepsy.

Now we are hoping to develop a new test that will enable us to isolate blood cells that contain Pgp and investigate how it functions within those cells. Using our flow cytometer (above) and DNA sequencer (page 16), we hope to look at blood samples from 200 people with drug-resistant seizures and 200 with newly diagnosed epilepsy. This will help us to better understand the function of this protein in people with epilepsy.

Following this project, we hope to be in a position to use this type of test to work out which people's drug resistant-epilepsy is caused by overactivity of P-glycoprotein.

Juliet and Steve's story

The arrival of Juliet and Steve's beautiful baby son, Samuel, has brought an end to years of heartache for the couple. They lost their first son, Christopher, due to problems connected with Juliet's epilepsy.

During her first pregnancy, Juliet was prescribed sodium valproate, an anti-epileptic medication that for some women can increase the risk of malformation, autism or neurodevelopmental disorders in their unborn child. Juliet is now taking leviteracetam.

'Research into anti-epileptic drugs is particularly important to us,' said Juliet. 'Sodium valproate is a brilliant drug for men and for women and girls who are not of childbearing age. But we hope that research at Epilepsy Society will help to work out whether a woman's genes might influence the way she responds to drugs such as valproate and the risk of her baby being affected.'

'Losing Christopher was incredibly painful. We don't want any other family to go through what we went through.'
Juliet and Steve pictured with baby son Samuel.



Lamotrigine and the Pill

Keeping drug concentration levels stable in the blood is important in ensuring optimum seizure control.

Sometimes, taking other medication alongside epilepsy drugs can reduce their efficacy, leaving people at risk of breakthrough or increased seizures.

Women with epilepsy are often prescribed lamotrigine, on its own or in combination with other anti-epileptic drugs. We wanted to find out whether the effectiveness of lamotrigine was altered when taken with the oral contraceptive pill.

As part of SEIN – Stichting Epilepsie Instellingen Nederland – we took part in a Dutch study which looked at women who were taking lamotrigine on its own with the oral contraceptive pill, and those who were also taking sodium valproate or carbamazepine.

Our results showed that when women take the oral contraceptive pill alongside lamotrigine, either with or without carbamazepine, the levels of lamotrigine in the blood significantly reduce. However when oral contraceptives were taken alongside lamotrigine and sodium valproate, drug levels in the blood remained stable.

Our research shows that women who take oral contraceptives and lamotrigine could be at greater risk of seizures. It is really important that levels of lamotrigine serum in the blood are measured using therapeutic drug monitoring.

The results should not be seen to promote the prescription of sodium valproate to women of childbearing age, however. Caution is needed with this drug due to the increased risk of foetal malformations in the children of women who take it during pregnancy.

Professor Ley Sander, medical director

AEDs and memory problems

We have been looking at the effects of different anti-epileptic medications on measures of cognitive function. We were particularly interested in looking at the impact that certain drugs and drug combinations can have on cognitive processing speed and working memory.

Processing speed is the speed and ease with which we take in information from the world and make sense of it. Working memory refers to the ability to hold information in the mind and manipulate it at the same time. We use working memory for mental arithmetic and problem solving.

Difficulties in both of these processes often lead to memory complaints. Slowed processing can mean that someone does not have enough time to take in new information in real world situations where it is not possible to slow the flow of the information, such as a TV news bulletin.

Our study found that while many anti-epileptic drugs have a detrimental impact on processing speed and working memory, other aspects of cognitive functions such as vocabulary and reasoning skills, remain unaffected by the drugs. Unsurprisingly we found that the more anti-epileptic drugs someone takes, the slower their processing speed tends to get.

This information has a number of practical uses. It helps us interpret the neuropsychological tests that many people with epilepsy undertake. We can work out which cognitive complaints are most likely to be due to the epilepsy and seizures and which may be due to the medication someone is taking. If the cognitive problems are really disabling, the consultant may consider changing medications to try to reduce the difficulties they cause in everyday life.

We can also use this information to help people find ways around the nuisance that the side effects of some anti-epileptic medications can have, by using the cognitive functions that are unaffected to develop compensatory strategies.

Dr Pam Thompson, head of psychology

To find out more about pregnancy and epilepsy go to www.epilepsysociety.org.uk/pregnancy-and-parenting or order our Pregnancy and parenting leaflet at <http://shop.epilepsysociety.org.uk>

It's not just the epilepsy

The impact of epilepsy extends beyond coping with seizures. Memory problems and mood disorders can be a constant challenge for many people with epilepsy. Around 600 people in the UK lose their lives every year to Sudden Unexpected Death in Epilepsy (SUDEP) and research shows that a person's life expectancy may be reduced if they have

other conditions alongside epilepsy. Our psychology team, below, is exploring strategies to help people cope with memory issues and they are investigating the link between epilepsy surgery and depression. We are also trying to identify genetic changes which may increase a person's risk of SUDEP or risk due to a combination of conditions.



Our psychology team: top row: Dr Pam Thompson, head of psychology, Dr Jacqueline Foong, neuropsychiatrist, Dr Sallie Baxendale, neuropsychologist
Bottom row: assistant psychologists, Liz Donnachie and Katherine McGrath, and research psychologists Rebecca Pope and Hanne Conn.

Can we train our memories?

Memory problems rank highly in the concerns of people with epilepsy. A poor memory can affect us in many ways. Studying and work become a struggle, time with family becomes less enjoyable, confidence and self-esteem suffer.

Over several decades our research has identified many causes of memory problems including faulty wiring in the temporal and frontal lobes, surgical treatment, medication and low mood. While we know lots about the causes we know little about what strategies may help people improve their memories or cope better with these difficulties.

Thanks to a research grant from Epilepsy Action the epilepsy group has undertaken a study exploring the effectiveness of memory training and the role of internet brain training exercises. The study looked at people with temporal lobe epilepsy complaining of memory problems.

Fifty-nine adults completed the programme. Twenty-three had been seizure free for at least one year and all but four were taking anti-epileptic drugs.

Participants were randomly placed in one of four groups:

- traditional memory training including external memory aids such as diaries, phone reminders and apps, and internal memory aids such as visual imagery to recall names
- internet brain training exercises – subscription was paid to a brain training website offering games using working and episodic memory, attention and processing speed
- traditional brain training together with internet exercises
- no training.

Our initial results show some benefits of memory rehabilitation in people with temporal lobe epilepsy who have memory problems. Improved memory test performance was greatest in those using traditional memory training. While our findings do not show any additional benefit to memory from on-line brain training, participants undertaking the internet exercises showed some improvements in mood.

After the study, the group with no training was given memory training and access to on-line brain training.

Dr Pam Thompson, head of psychology

Assessing the risk of surgery

Low mood often goes hand in hand with epilepsy and this has been a focus of recent research. With the support of a grant from the Henry Smith Charity the epilepsy group has been exploring the impact of brain surgery on mental health.

Our recently published studies demonstrated that people with temporal lobe epilepsy and a history of psychiatric problems were not only more likely to show symptoms of mood disorders after surgery but were also less likely to become seizure free.

Our current research findings have suggested that symptoms of depression following temporal lobe surgery increase when there are signs of pre-existing cognitive and behavioural brain disturbance outside the temporal lobe. This year we have been extending our research to include people undergoing surgery on frontal brain regions.

Developing depression or an anxiety disorder following surgery can be devastating even when seizures are fully controlled. The stigma of having epilepsy is replaced by the stigma of having a mental illness. The outcome is worse still for those individuals with continuing seizures after surgery who also develop psychiatric complications.

Our research findings are enabling us to provide more detailed information to people with epilepsy and their families to help them in the surgical decision making process. People need to know not only what are their chances of becoming seizure free but also what are their risks of developing a memory or a psychiatric disorder.

Dr Jacqueline Foong, consultant neuropsychiatrist

Do our genes make us susceptible to SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) is thankfully rare. Around 600 people in the UK die from SUDEP in the UK each year. This means the risk for those with epilepsy is about 1 in 1000. But we believe that many of those deaths might be preventable.

One of our key areas of research is trying to understand what causes SUDEP in some people but not in others. We also want to learn how we can prevent it from happening. One of the ways we are doing this is using genetic sequencing to see if a person's genes can pre-determine their susceptibility to SUDEP.

We have been carrying out a study into the genetic susceptibility of people to SUDEP. We are looking at the sequence of the genome, comparing the genetic

information from people who lost their lives to SUDEP to information from those with epilepsy who have lived with the condition for many years.

Preliminary results from sequencing suggest some genetic differences between those who died earlier from SUDEP and those who survived. The research is ongoing and we are hoping to be able to report further findings in the not too distant future.

Professor Sanjay Sisodiya, lead geneticist

If you would like to find out more about SUDEP, please go to www.epilepsysociety.org.uk/sudep

Epilepsy and other conditions

Studies have shown that people with hard-to-treat epilepsy may have a reduced life expectancy in comparison with the general population. We used to think that seizures and their underlying causes were the main reason for this increased mortality risk. Our studies of large groups of people with epilepsy have now shown that certain other conditions seem to be very common among this community and may in themselves contribute to the risk of early death. This is not including those who lose their lives to SUDEP.

Depression, anxiety and psychosis are more common among people with epilepsy and worldwide studies have added to the evidence suggesting that these form a major risk factor for early death including suicide, vehicular and non-vehicular accidents, and assaults.

Several medical and neurological conditions are also

implicated. Cardiac, gastrointestinal and respiratory disorders, strokes, dementia and migraine are common among people with epilepsy and may well contribute to increased risk factors.

The association between epilepsy and other conditions can be due to a variety of genetic, biological and environmental factors. We are just beginning to study the genetic basis of these issues in the hopes of understanding the link between different conditions and reducing the risk of premature death.

What is certain is that for a condition which is so often accompanied by other illnesses, our mantra should always be 'epilepsy and what else?' while management of these conditions should always be part of a holistic approach.

Professor Ley Sander, medical director



Emma with Oliver, left, and Joe, right

Remembering Jamie

In June 2011, Emma Stewart and Leonard Lewis lost their youngest son, James, to Sudden Unexpected Death in Epilepsy (SUDEP). He has two brothers, Joe, 31, and Oliver, 28, and a step sister Lana, 11. Here the family talks about James' life and their hope that his legacy will make a difference for others with epilepsy in the future.

Emma From the moment Jamie was born he was different but always wonderful. He had a heart murmur and hypertrophic cardiomyopathy which is a thickening of the arteries. At the age of two he was diagnosed with Noonan's syndrome, a rare condition that affects stature and facial characteristics and can lead to seizures.

Leonard James had a special and unique sense of humour. He had to put up with a lot, but never let his medical struggles get him down.

Oliver He had a real love of sport. Jamie could absorb statistics on football, cricket, motor racing, golf...

Emma ...and he loved playing sport, although he was the least likely-looking sportsman you could ever see. He never minded if he was in the third team and lost, he just liked to join in.

Joe When he was little he had a permanent yellow bruise on his forehead from bumping into things. You couldn't stop him.

Emma Jamie was 14 when he had his first nocturnal seizure. He had come home from boarding school and was staying with me in a tiny flat so we were sleeping in the same room. It was quite a terrifying experience.

Joe Epilepsy affected Jamie more than any of his other disabilities. He hated taking the medication. It made him feel drowsy, depressed and often forgetful.

Emma Getting Jamie to take his medication was a battle. I was aware that you could die from epilepsy and I wanted the doctors to spell out the dangers to him. But they only told him if he didn't take the tablets he would have a seizure. I bought him a safety pillow, but it stayed in the cupboard.

Joe In his last few years, Jamie discovered a real talent for art. He was just completing his art foundation and had been accepted to do a BA in arts.

Emma Jamie was 23, living by himself in London and very independent. I think we all started to relax a little. It was June 2011 and he was going

to be coming to me for the weekend but texted to say he was busy.

Oliver I called him on the Saturday as Manchester United was playing in the Champions League. When there was no reply, I assumed he was watching the match with friends at the pub. I called again on the Sunday as it was the Monaco Grand Prix – again no reply. On Monday morning I called Joe.

Joe I think I half knew. We found Jamie in his bed.

Oliver Looking through Jamie's camera, we discovered he had been on a protest bike ride against London traffic on the Friday night – there were pictures of him in Trafalgar Square, Tower Bridge, living life to the full, right to the very end.

Emma I ask myself would things have been different if Jamie had come to me that weekend, but I don't think we could have stopped things happening.

Leonard In 2011 we launched the James Lewis Foundation which invests in epilepsy research and treatment. It is also supporting a 3,500 mile rowing challenge by two people, one who has epilepsy. So James is still very much making an impression.

Emma We all hope the foundation will make a difference in the future for others with epilepsy. My one wish would be that we could better predict the likelihood of seizures and identify those at greatest risk of SUDEP.

Joe Over half the epilepsy deaths in the UK are due to SUDEP. If we can understand why and reduce this, we will be taking a giant step forward.

The James Lewis Foundation has provided significant funding for Epilepsy Society's DNA sequencer and other medical equipment at our research centre. It has also helped to fund our helpline.

New Life Foundation was also established by the Lewis family in 1991 to provide informed support for disabled children, their families and carers.

Inside our laboratory

DNA sequencing

The installation of a DNA sequencer at our research centre has opened a new chapter in the diagnosis and treatment of epilepsy. Our researchers will be able to map the genomic sequence of a patient rapidly and efficiently on site. These findings will then be interpreted alongside existing tests such as MRI (magnetic resonance imaging) and EEG.



Research associate Laura Hernandez uses a **centrifuge** as part of the process to extract DNA from 5-10ml of blood.



Research associate Bridget Maher measures the amount of **DNA** extracted from a blood sample.



DNA encoding the exome is loaded onto a microchip and placed into the **DNA sequencer**. DNA can be sequenced within two days but data can take several weeks to analyse.



Bridget and Laura quantify the DNA by measuring it at regular intervals throughout the sequencing process, as a control measure.

Inside our research centre

Clinical research

We are using cutting edge technology to help us unravel the biology of epilepsy. Using the most advanced techniques, we are able to look deeper into the brain and to understand better the genetic contribution to the condition. We hope these techniques will become part of a person's routine assessment in the future.



Using **Optical Coherence Tomography (OCT)** we are able to look at the thickness of retinal fibres at the back of the eye in relation to epilepsy severity, duration, drug resistance and epileptogenic focus.



Our **3D imaging camera** helps us to explore the link between face shape and genetic variations which can lead to epilepsy. Research shows that there can be subtle changes in shape in particular types of epilepsy, but these are very varied.



Transcranial magnetic stimulation uses a powerful magnetic field to study brain excitability in people with epilepsy. We are using it to look at how the brain responds to anti-epileptic drugs and the ketogenic diet.



Functional magnetic resonance imaging (fMRI) scans are helping us to predict the outcome of brain surgery, individual responses to medication and to map memory in the brain.

Advances in epilepsy surgery

Professor Matthias Koepp



Almost 50 per cent of people with difficult-to-control epilepsy remain seizure free five years after epilepsy surgery. Yet of the 1,000 people identified in the UK each year as being suitable for epilepsy surgery, less than half undergo treatment. One of the concerns many people have is the potential damage to important brain functions, such as memory, language and vision. Up to 40 per cent of those with temporal lobe epilepsy who undergo surgery are at risk of a decline in these areas.

One of our key areas of research at Epilepsy Society is to identify critical areas of the brain using structural and functional neuroimaging to optimise the safety and success of neurosurgery.

It is 20 years since we installed our first magnetic resonance imaging (MRI) scanner at the Chalfont Centre. We have recently updated the scanner to generate the most advanced images of the brain. We hope this will help us further in revealing the epileptogenic zone and defining pathways critical for memory, language and vision.

Functional MRI (fMRI) enables us to measure blood flow changes in the brain and diffusion-tensor imaging (DTI) allows us to study intricate white matter networks in much greater detail. This provides neurosurgeons with images that map critical networks and so minimises the risk of damage to cognitive abilities or visual fields.

Tracts vital to support language skills or visual pathways

are located in the temporal lobe. If a surgeon were to cut through these, it could affect language and vision.

Our research has shown that when there is damage to the left side of the brain, the right side of the brain can partially compensate with language and memory skills migrating to the right hemisphere.

Using fMRI we have shown that the more you use your left temporal lobe to remember things before surgery, the bigger the hit your memory is likely to suffer after surgery to this area. However, if language and memory skills have already started to migrate from the left to the right side of the brain, this helps to reduce cognitive deficit post surgery.

Our research suggests that to maximise the migration of cognitive skills to unaffected areas of the brain, it might be helpful for a person to engage in re-organisation pre-surgery, in consultation with their neuropsychologist.

One of our most exciting current projects is the design and development of the Epilepsy Navigator, an interactive 3D neuronavigation system that will simultaneously display critical brain functions, lesions, arteries, veins, blood vessels and white matter tracts connecting areas of the brain.

The system being developed under the leadership of Professor John Duncan, clinical director at the National Hospital for Neurology and Neurosurgery (NHNN), will enable neurosurgeons to plan the best operative approach for inserting recording electrodes in the brain and for planning surgery. We hope that this will result in even more precise operations, with a higher cure rate and fewer complications.

The system has already been assessed during 15 presurgical investigations and surgical treatments at the NHNN. The system was used to support discussion around

Anti-epileptic drugs do not work for everyone. Around 30 per cent of people with epilepsy continue to have uncontrolled seizures in spite of trying several different drugs. So it is important that we explore other treatment options for those who do not respond to conventional medications. Our research is focusing on two alternatives – epilepsy surgery and the ketogenic diet.

When medication doesn't work

treatment, planning of surgery, implantation of electrodes in the brain, surgery and outcomes and was found to be beneficial in all 15 cases, including the two examples here:

Patient A 30-year-old man with uncontrolled seizures generated in the left frontal lobe, close to critical pathways for language and for hand movement.

Epilepsy Navigator was used to guide accurate placement of intracranial electrodes for recording seizures and mapping vital networks. Also used to guide surgery.

Outcome patient has been seizure free for 15 months since surgery which had no negative impact on hand movement. Minor speech deficit improved within three months.

Patient B 28-year-old woman diagnosed with tonic seizures. These were thought to be generated in the right frontal lobe with involvement of the supplementary motor area, part of the network that controls movement.

Epilepsy Navigator used to map areas for hand movement and the corticospinal tract which conducts impulses from the brain to the spine. The supplementary motor area was removed as it was part of the seizure onset zone.

Outcome: the patient experienced mild weakness on one side of the body post surgery. This resolved itself completely after two weeks with the brain able to recover function after removal of the supplementary motor area. Four months after surgery she came off all medication and 12 months after surgery remained seizure free.

Professor John Duncan



Emma's story

'Six years ago I had a temporal lobectomy to remove the scarred area of my brain that was causing my seizures, and from the moment I woke up I have been seizure free. If I hadn't had the operation, I don't think I could have got through my three years as a student nurse as seizures took up a massive part of my life. I've experienced firsthand how much research has helped improve treatment since I was diagnosed 18 years ago, and how much it can help change the lives of people like me. With research constantly improving, I believe things can only get better, and more people can hopefully get the specific medical help needed to control their epilepsy.'

Emma Johnstone

The ketogenic diet

Professor Sanjay Sisodiya



We know that some children with epilepsy who do not respond well to traditional anti-epileptic drugs (AEDs) have benefited from the ketogenic diet. This is a high fat, low carbohydrate, protein controlled diet that has been used since the 1920s for the treatment of epilepsy.

Usually the brain uses glucose from carbohydrates for its energy source. In the ketogenic diet, the brain's energy comes from particular fats, called 'ketone bodies', instead of glucose. For some people this type of ketone-producing diet helps to prevent or reduce the number or severity of seizures.

Although the diet can be effective in some children, we have no means of predicting which children will benefit. There is also limited data relating to the use of the diet in adults.

We are carrying out a detailed DNA analysis of two groups of children – those for whom the ketogenic diet has worked, and those who have not responded to the diet. Our aim is to identify the genetic factors associated with

a positive response to the ketogenic diet, as part of a wider investigation into the genetics of epilepsy and its treatment.

We hope that by isolating the genetic factors predisposing a person to respond well to the diet, we can explore other ways to reproduce the beneficial effects of the diet.

We have already found that parents of children on the diet have a very positive attitude to the regime and that this has a significant impact on the response of their children to the diet. However, more than half of parents questioned expressed concerns about the potential long-term effects of the diet.

We have also carried out a small audit of adults following ketogenic diet therapies and this has shown promising results. Working with researchers in London and the Netherlands and with the charities Young Epilepsy and Matthew's Friends, we looked at 23 adults with uncontrolled epilepsy who were following the ketogenic diet or the modified Atkins diet. This is also high in fats and low in carbohydrates.

Response rates were similar to those in children. Thirty-nine per cent of adults on ketogenic diet therapies showed a 50 per cent or more decrease in seizure frequency. Sixty five per cent were brighter and more alert and 61 per cent had less severe seizures. These results highlight the need for further studies into the use of the ketogenic diet in adults.



Join our brain donation register

The Epilepsy Society Brain and Tissue Bank provides a vital donation facility and resource to support research into epilepsy and the development of new treatments. Gabriella Wright is manager and researcher at the brain and tissue bank. She is also the first port of call for anyone considering joining the brain donation register. As the facility marks its first birthday, she talks about brain donation, her beloved dad and the importance of family.



I really want people to understand the value of the Epilepsy Society Brain and Tissue Bank. I want everyone to know how important brain donation is and the vital part it can play both in helping us to understand the causes of epilepsy and in finding new treatments, even a cure. There is still such a stigma and a taboo around epilepsy that really adds to the burden of living with the condition. Teenagers with epilepsy have to cope with the embarrassment of having a seizure. Adults with uncontrolled seizures may face losing their jobs and their means of supporting their family. We need to really celebrate and value the empathy and kindness of those who choose to join the brain donation register and carry a donor card, knowing that their gift could mean better seizure control and a better quality of life for generations to come.

Our brain tissue potentially holds the answers to the questions we are asking – why do people have seizures, why do they occur in certain parts of the brain, why do they stop as suddenly as they begin, why do some people have a high seizure threshold while others have a low one. The brain is a labyrinth of uncharted connections. The only way we can unravel its mysteries is by studying brain tissue samples on a large scale.

Deciding to donate your brain at the end of your life is a big decision to make. It doesn't just involve the person themselves but also their family and friends. Loved ones need to be comfortable that this is what the donor really wanted to do. As a mum of three children, I can totally appreciate that it might be hard for a family who have just lost a parent or relative to then think of someone removing such a very vital part of that person. I reassure my donors and their families that the brain is removed with the utmost care and respect. When a brain is delivered to our laboratory, we treat it as something precious, always bearing in mind the selfless decision that this person has made earlier in their life, always thinking of that person's family and friends.

If I were to die tomorrow, I would be happy to think that my brain could push forward the boundaries of medical research, or that one of my organs would give someone else the precious gift of life. I want my children to know how I feel and to understand that this would be my legacy. Family is really important to me. My dad was diagnosed with multiple sclerosis when I was five years old and spent the last 8-10 years of his life in a wheelchair. He was an amazing man and such an inspiration. I think that seeing how he lived his life,

not allowing multiple sclerosis to hold him back, has really helped me to develop empathy for others.

When my dad died, I really needed to find out everything there was to know about multiple sclerosis.

It was my way of staying close to him and knowing him more. I have had many part-time jobs from hairdresser to working in administration so I could be with my children when they were young. But when the time was right I decided to follow my passion and study for an honorary degree in biomedical science. My dissertation on multiple sclerosis led me to pursue further study into the function of the brain through a master neuroscience programme which included the very latest techniques in brain mapping and research into neurodegenerative diseases.

As a member of the team at the Epilepsy Society Brain and Tissue Bank, I feel as though everything I have been working towards all my life has finally come together. It draws on my organisational skills, my passion for research and my empathy for other people. Whether I am talking to potential donors, families, friends, coroners or neuropathologists, I feel I can relate to where they are in their journey. And always, beside me, my dad is my strength.

The Epilepsy Society Brain and Tissue Bank is generously supported by The Katy Baggott Foundation which was set up to provide funding for research into epilepsy and particularly Sudden Unexpected Death in Epilepsy. The bank is based at the National Hospital for Neurology and Neurosurgery at Queen Square, London.

To find out more or to join our brain donor register

Visit www.epilepsysociety.org.uk/brainbank
 Email epilepsybrainbank@ucl.ac.uk
 Call 020 3448 4009

Epilepsy: a global issue

Epilepsy affects over 60 million people worldwide, with the majority living in low and middle income countries where access to medical treatment may be limited. Professor Ley Sander works with the World Health Organisation's (WHO) global campaign against epilepsy to improve the way epilepsy is managed in resource-poor countries including China, Brazil, Ecuador, Georgia, Bulgaria, Kenya and Senegal.

Research suggests that globally the number of people with active epilepsy seeking treatment would increase by 11 per cent if they believed anti-epileptic drugs (AEDs) were effective; by 12 per cent if health facilities providing AEDs were less than 20km from their homes; and by 40 per cent if AEDs were free. Our epilepsy group is recognised as a WHO Centre of Excellence.



Brazil

The epilepsy group has been looking at the best ways to deliver primary care in rural areas. Our project has provided the embryo for National Epilepsy Programmes in both Brazil and China (see right). In Brazil, epilepsy management has now been incorporated into the family medicine programme and has reached a third of Brazilian municipalities. Similar projects are now being devised for Ghana, Cameroon, Vietnam and Myanmar.



China

There are an estimated nine million people in China with epilepsy. A new model of primary care (see left) has reached over 30,000 people in 15 provinces, with epilepsy becoming a national health priority. The Chinese government has committed to establishing a network of epilepsy centres across the country. The epilepsy group has also been investigating the causes of death and premature mortality risk in people with epilepsy. The highest risk factors were cerebrovascular disease, drowning, self-inflicted injury, status epilepticus and Sudden Unexpected Death in Epilepsy. The risk of drowning was higher for those with epilepsy living in a rural waterside area.



Africa

Ten million people in Africa are affected by epilepsy and 80 per cent of those are not treated with modern medication. The prevalence of epilepsy in sub-Saharan Africa seems to be higher than in other parts of the world and possibly caused by risk factors including parasitic diseases and poor antenatal and perinatal care. The epilepsy group has been working with the University College London Institute of Child Health to carry out a large project focusing on the patterns, causes and effects of epilepsy, as well as the delivery of healthcare. Our aim is to characterise and understand epilepsy in each of the regions of Africa.



Georgia

The epilepsy group has been looking at the knowledge, attitudes and stigma towards epilepsy in different social groups in Tbilisi, Georgia. We surveyed over 1,000 people divided into three groups: medical, non-medical professional, and unskilled or unemployed. We found that medics had a better knowledge of the condition but their attitudes towards epilepsy were the same as or worse than other groups. Of those questioned, 14 per cent would not let their children play with anyone with epilepsy and 75 per cent would not allow their children to marry someone with epilepsy. Nearly one third of teachers thought epilepsy was a psychiatric disorder. This underlines the need for greater public awareness.

The work represented here is not funded by Epilepsy Society

Making changes



Have you ever answered one of our surveys, responded to one of our requests for 'real life experiences' or taken part in a focus group?

If you, have then the chances are you will have contributed to our 'social' research. Social research looks at problems, situations or human behaviour with a view to influencing change or solving the problem.

How and why we choose issues for social research is more often than not down to you – our supporters. Through our social media channels we keep an eye on hot topics – and where we start to see trends we look more closely to see if there is an issue which needs tackling.

And we work with charity partners, such as the Neurological Alliance and Disability Benefits Consortium to raise the profile of epilepsy to commissioners and influencers.

Taking the tablets

More than 1,000 people took part in our medication survey. Managing epilepsy is more than just taking the tablets, but taking medication in the way it's prescribed is key to seizure freedom. We wanted to know how adherent people with epilepsy were, whether side effects influenced how they took their medication, and whether those who were seizure free were more adherent than those with ongoing seizures because they had more to lose. We hoped that by understanding more about the way people took their drugs we might be able to see if there were particular issues which could be addressed.

So how has the survey influenced our work? Our recently reprinted new medication booklet has been updated with a renewed focus on adherence – including tips on how to optimise

taking your medication.

We've also used some of the results to evidence work around consistency of supply of medication. In a recent submission to the Medicines and Healthcare Products Regulatory Agency (MHRA) we were able to demonstrate that switching between branded and generic drugs and from one generic to another really is an important issue for people with epilepsy.

The extra cost of living with epilepsy

We know that epilepsy is an individual and variable condition – but is there an additional cost to living with a long-term fluctuating condition?

That's the question we posed to people with epilepsy to ensure their voice was heard as part of a wider consultation by the charity Scope, which is looking to drive down the cost of living with a disability.

From your feedback we were able to submit a report demonstrating that there are financial inequalities to living with epilepsy.

A common complaint was the difficulty faced in obtaining insurance. From our research we found that as many as 36 per cent of people with epilepsy have been refused one or more types of insurance. Others told us that premiums had been bumped up to 'exorbitant' rates even though they had not had a seizure for years.

The cost of transport was an issue. People with epilepsy and unable to drive are entitled to concessionary off-peak bus passes – but these cannot be used for commuting to

work before 9.30 am. Dependency on public transport at peak times often led to higher costs for working people with epilepsy. Others chose not to use public transport – but preferred to use taxis to avoid stress and anxiety.

Safety equipment, such as seizure alarms or domestic equipment designed to safely undertake routine domestic tasks also incurred additional costs.

For people with uncontrolled seizures, damage to personal items was a cost issue. No financial support is available for health related costs such as dental treatment or damage to glasses.

The list goes on but we hope that by making the case for epilepsy we will be able to influence current legislation.

What's on our radar

For women and girls with epilepsy there are particular issues around medication. Some drugs are known to affect contraception, others are contra-indicated in pregnancy. We want to know how much women themselves and health care professionals are aware of the issues.

You can take part in our survey at www.epilepsysociety.org.uk/epilepsy-treatment-you-survey

And the prevalence of epilepsy in later life is on the increase as people live longer. Are there particular issues which relate to the older population?

If you would like to help our social research go to www.epilepsysociety.org.uk/campaign

Become a research associate member and help us find a cure for epilepsy

We believe our research programme offers the best hope of finding a cure for epilepsy. The more we do, the sooner that day will come. By becoming a research associate member you can help us to continue our ground-breaking medical work.



Professor Sanjay Sisodiya, our lead geneticist, takes members on a tour of the Epilepsy Society Research Centre at our research associate members' seminar 2014.



Professor Matthias Koepp explains to members how neuroimaging can help to predict and improve outcomes in epilepsy surgery.

How much does it cost?

Research associate membership costs £50 per year, enabling you to make a direct contribution to our world leading epilepsy medical research. (If you are already an associate member, you might like to consider upgrading your membership.)

Your research associate membership would include

All the benefits of associate membership:

- *Epilepsy Review* magazine (three issues per year), packed with articles on the latest medical research, treatments and lifestyle issues about epilepsy
- an epilepsy information pack, with seizure diary, epilepsy ID card and membership badge
- access to more information through the members area of our website and fast track access to our online forum
- priority booking for our popular annual conference.

Plus:

- our annual research update
- the chance to attend our annual research associate members' seminar and hear from epilepsy experts.



Marie-Christine Poulain

'My brother has had epilepsy for many years so I have seen how

research into the condition has helped him, particularly with developments in imaging and medication. As a research associate member, I hear from leading researchers about the latest developments and I know that my membership helps to fund research that will hopefully make a difference for people with epilepsy in the future.'



Paddy Kuon

'If the mind was simple enough to understand, then we would be too simple to understand

it. But, the more we know, the more we can deal with our fears and uncertainties. My membership is part of an effort to try to turn something frightening into something fascinating. I would also like to believe that I will have contributed towards further research through tests that weren't just for my own immediate good.'

How to join

You can join or find out more:

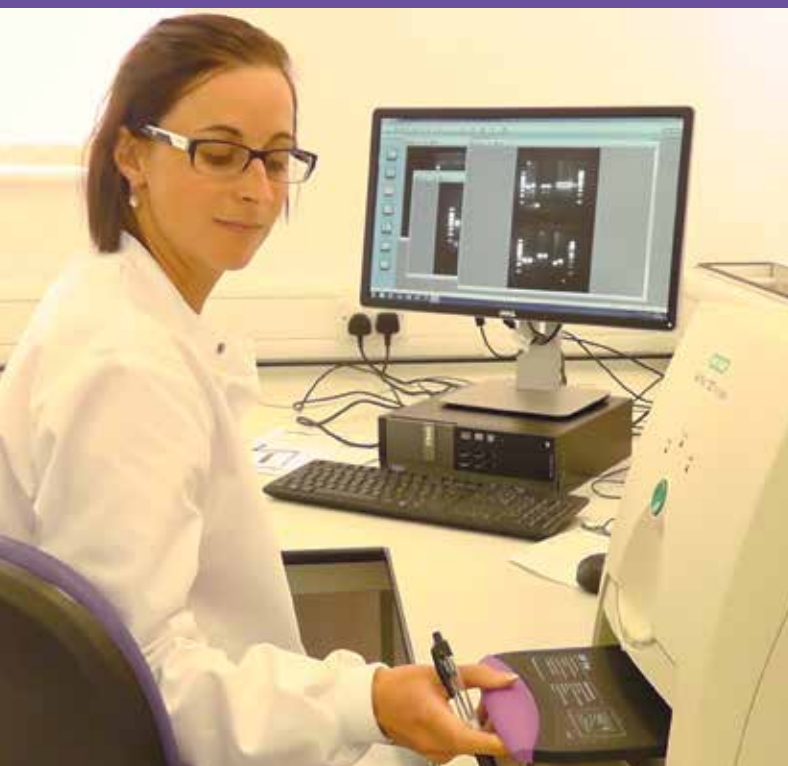
Online www.epilepsysociety.org.uk/become-member

By phone 01494 601 402

By Email members@epilepsysociety.org.uk

Thank you

We would like to thank all those individuals and organisations who have supported Epilepsy Society over the past year and a special thank you to our research associate members. Your generosity is helping us to push forward the boundaries of research and to make a difference to the lives of people with epilepsy.



**epilepsy
society**

a full life for everyone
affected by epilepsy

www.epilepsysociety.org.uk
01494 601 300

Confidential Helpline – 01494 601 400
Monday to Friday 9am – 4pm,
Wednesday 9am – 8pm.
National call rate. Information
and emotional support.



Epilepsy Review magazine

If you would like to receive future copies of *Epilepsy Review*, call our membership office on 01494 601 402 or visit www.epilepsysociety.org.uk/membership