

focus



Epilepsy Research UK Newsletter

Spring 2009

National Epilepsy Week focuses on government under-funding of epilepsy services

Epilepsy services are drastically under-funded by the government. Despite the fact that 456,000 people are affected in the UK, only about 93p per patient goes towards treatment each year. Moreover there are approximately 400 avoidable deaths from epilepsy each year and 69,000 people experience seizures needlessly. The management of epilepsy is so inefficient that £189 million is wasted each year, due to incorrect diagnoses.

The government desperately needs to tackle this situation, but also needs to provide more funds for research into epilepsy deaths, drug efficacy and improved diagnostic techniques.

Epilepsy clearly needs to be higher on the political agenda, but studies have shown that there is very little awareness about it amongst MPs. A survey carried out in 2007, found that almost 90 per cent of the MPs questioned did not know (even roughly) how many people in the UK have epilepsy.

We need your help to raise the profile of epilepsy in the government

This year, National Epilepsy Week (NEW) will take place between 17 and 23 May 2009. On Wednesday 20 May 2009, Epilepsy Research UK and other members of the Joint Epilepsy Council (JEC) are organising a national lobby of parliament, to put pressure on politicians to commit to making improvements in epilepsy care. This lobby will take place at 2.30pm, in the Jubilee Room, Westminster Hall, House of Commons, London SW1A 0AA.



To make this a success, it is crucial that a large number of people take part, and that as many MPs as possible attend. You can help to make this happen by writing to your local MP and inviting him or her to meet you at the event. It will be an excellent opportunity for you to talk about your, your relative's or your friend's experiences of epilepsy, and to encourage your MP to commit to taking action.

The more MPs we have on our side, the louder our voice will be, so please join us. It needn't take long. We have prepared a template letter to your MP, which you can download and amend accordingly. Please visit www.epilepsyresearch.org.uk.

We look forward to seeing you, and your local MP, on 20 May 2009

For more information about the NEW campaign, please contact Delphine van der Pauw on 020 8995 4781, or at delphine@eruk.org.uk.

Research news

Reports from a selection of the research projects completed in 2008

Sodium channels and epilepsy

Dr Andrew Makoff and his team from King's College London Institute of Psychiatry, King's College Hospital and Kent & Canterbury Hospital, completed a 24-month project looking at the link between sodium channels and epilepsy.

Sodium ions play a vital role in creating electrical signals, and they enter / leave neurons and other cells via sodium channels. There are several types of sodium channels, encoded by different genes, and a fault in any of these genes will cause the corresponding channel to behave abnormally. It might be that too much sodium enters specific neurons and causes them to become hyperexcitable (leading to seizures).

Sodium channel genes known as SCN1A, SCN1B and SCN2A have already been linked to rarer forms of epilepsy, but the team wanted to see if sodium channels also play a part in common epilepsies. They were especially interested in generalised epilepsies in younger people who are otherwise well, where a genetic cause is more likely.

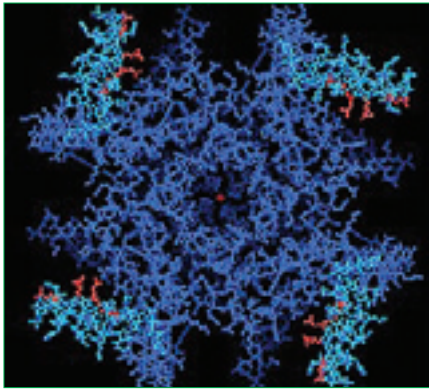
The group collected DNA from a group of epilepsy patients and their parents, along with a set of controls (people without epilepsy), and examined it for genetic abnormalities that might be associated with epilepsy.

Continued on page 2

**funding research
changing lives**

Continued from page 1

Having identified these faults, known as 'markers', the scientists then pooled the DNA from a group of 226 people with epilepsy and 223 controls, and screened both sets to see if there was a difference between the two groups in how frequently each marker appeared. In this way the genes with a strong association to epilepsy could be pinpointed.



Out of 85 markers screened by DNA pooling, the team identified 15 markers (in 4 genes) that should be examined more closely. Of these 15, two markers (in 2 genes) were found to be associated with epilepsy. One of these markers, in a gene known as SCN2A, was particularly interesting, as it was especially apparent in the epilepsy patients who had a history of febrile seizures. The other marker, in SCN1A, was associated with all common forms of epilepsy in our sample.

These results are exciting, because if replicated by other researchers, they will confirm that SCN1A and SCN2A are linked to common forms of epilepsy. If this is indeed the case, scientists can look into new treatments that counteract abnormalities in this gene.

The long-term effects of surgery for children with temporal lobe epilepsy

Dr Torsten Baldeweg of the Institute of Child Health in London, completed his 18-month study into the long-term effects of surgery for temporal lobe epilepsy (TLE) in children.

Surgical treatment for TLE that has not been controlled with AEDs is relatively common, and is effective in controlling seizures. Previous studies of adult patients who had had surgery for TLE in the left-hand side of the brain found that patients may lose a significant amount of

verbal memory and learning ability after the operation. This is because the left side of the brain controls language function in general, and the area of the brain being operated on, the left temporal lobe, is particularly involved in verbal memory. This memory impairment can significantly reduce the patient's quality of life and work performance. The effect appears to get worse in the long-term.

Dr Baldeweg and his colleagues recruited and tested 31 patients (children aged 15 years or more, who had surgery for their epilepsy at Great Ormond Street Hospital more than 5 years ago) and 11 non-surgical control cases. They tested memory and intelligence and carried out detailed MRI scans.

As in adult populations, verbal memory in patients who had surgery on the left side of the brain was worse than that in patients who had surgery on the right side. However 86% of patients who had surgery became seizure free and 57% became drug free. This had extremely positive effects – increasing brain growth and IQ in the left-sided group, and raising mood and mental ability in general.



The results show that surgery can be a very beneficial treatment choice for children with TLE, in terms of their mental ability and quality of life. Methods must now be employed to detect and treat appropriate patients early.

This project was supported by our memorial funds in 2005.

Can the onset of temporal lobe epilepsy be delayed?

Dr Mala Shah and Professor Matthew Walker, at the Institute of Neurology, University College, London concluded their project looking at whether the onset of epilepsy can be delayed.

It is thought that temporal lobe epilepsy (TLE) develops after the occurrence of

damage to the brain. This could be due to events such as traumatic head injury, stroke or status epilepticus. There is often a delay between the occurrence of this damage and the onset of chronic seizures, and this delay is called the latent period.

The excitability of certain neurones in an important memory section of the brain called the entorhinal cortex (EC) has been found to be significantly higher than normal during the latent period. This is due at least partly to a change in the nature of certain ion channels in the membranes of these cells. These channels, called h-channels, are opened or closed by the size of the difference in electrical charge between the neurone and the surrounding fluid. During the latent period, the number of h-channels decreases significantly, which makes these neurones more excitable and more prone to seizure activity.

Lamotrigine is a commonly prescribed anti-epileptic treatment, which has recently been shown to enhance the activity of h-channels in neurones. Dr Shah and Professor Walker decided to explore whether lamotrigine administered during the latent period would be able to restore h-channel numbers to normal, and delay the onset of TLE.

The results showed that lamotrigine can indeed increase the number of h-channels during the latent period, but, interestingly, numbers remain lower than normal. In addition, the effects of lamotrigine are only temporary and before long h-channel numbers decrease once again. Whether or not this drug can delay the onset of TLE is still being investigated.

This project will form the basis for exciting investigations in the future. It has shown that h-channel numbers in the EC can be restored after traumatic brain injury, but that more effective drugs need to be developed, for the full benefits of this to be explored.

This project was supported by our memorial funds in 2006.

None of this progress could have been achieved without your help, but there is still a long way to go. We look forward to your continuing support in the future.

National Epilepsy Week

We hope you'll join us in marking National Epilepsy Week, 17 to 23 May 2009, by hosting a fundraising coffee morning/afternoon tea or other convivial event in your home or workplace.

You can keep it small and simple and invite a few friends for tea or coffee, hope for good weather and plan a picnic or barbecue, or hold a drinks or dinner party, then ask all your guests to make a donation towards our research. Even if you're not able to host anything yourself, you may be able to arrange for a dress down day in the office or non-uniform day in school, or for your church collection or pub quiz night to be held for the benefit of Epilepsy Research UK during the week. Contact Shona or Jo in the office for a National Epilepsy Week fundraising pack.



Focus on fundraisers

TransAmerica Trail

"My name is Ella Hashemi, and I turned nineteen years old over the summer during my gruelling ten-week, 4255 mile journey from the west to the east coast of the USA.



Ella completing her TransAmerica ride

The TransAmerica Trail runs from Oregon to Virginia through lush coastline, snow-capped mountains, high deserts, rugged wastelands, sprawling plains, rolling grasslands, fertile farmlands and cool forests, taking in three major mountain ranges: The Cascades in Oregon, The Rockies in Colorado and The Ozarks in Missouri. My three friends and I were riding completely unsupported carrying our own tents, clothes, tools and spares, cooking equipment, water and food; this was nothing short of the most challenging experience of my life.

Before this trip the most cycling I had seriously done was one weekend away at a leisurely 20 miles a day. Achieving an average of 70-80 miles a day in hugely varied terrain and climate seemed like an utterly alien and unfeasible concept, especially as I was training whilst preparing and sitting university exams. The willpower for me even attempting and then completing such a task came from the cause I was cycling for: Epilepsy Research UK. My mother suffers from epilepsy, and seeing how much it affects her life every day made me certain that supporting this charity could make huge improvements to the standard of living of my mother and other sufferers.

Needless to say, even with all the punctures, heat waves and hurricanes (!), I had an absolutely amazing time. TransAmerica has changed my life and I hope that with the money I have raised by completing it, it will in time change the lives of others."

Our thanks go to Ella for taking on this intrepid journey for Epilepsy Research UK and for raising £3,012.

Student power

Students on the Childcare and Education course at City College



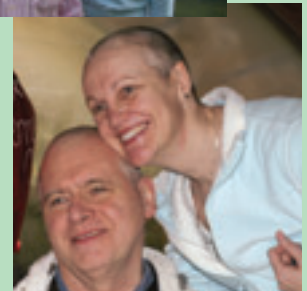
Coventry organised fundraising activities in college for two days to raise £310 in memory of fellow student Toni Marie Scanlon.

Head shaving for research

Cherry Michelli raised £1000 when she and supporting carer Phil Tucker both had their hair shaved off by Cherry's son Daniel.



Daniel and Cherry before, and Cherry and Phil after the deed was done!



Skydiving

Here in the Epilepsy Research UK office we remain in awe of those supporters who skydive to fundraise for our work!

Chloe Graham raised £1040 on her recent tandem skydive.



Christmas cards

Epilepsy Research UK cards sold well in a difficult Christmas trading season and our thanks go to all who supported us by buying our cards. We also thank all our dedicated volunteers in the Cards for Good Causes, Card Aid, Bromley Community Links and Ealing charity Christmas card shops without whose help we would not be able to participate in these shops. If you would like to join our team of card shop volunteers next Christmas, or know of an independent charity card shop we could approach to sell our cards, please get in touch with Shona Scott at the office or email shona@eruk.org.uk.

Sporting Events 2009

2008 brought us our most successful year to date in our sporting calendar. We had 143 runners take part in the Great North Run alone, 27 in the Great South Run, and were thrilled with the turnout of 32 at the Epsom Downs Dash! We also had people supporting us in the Bristol and Cardiff half marathons, a coast to coast cycle ride both in the UK and across America, along with many other entrants in all manner of events! We owe a big thank you to everyone who took part throughout the country in support of our work.



We are hoping 2009 will be even better so sign up to take part today! We have places in everything from a 5k fun run to a marathon. Whatever the event you will receive full fundraising support from us including a pack with fundraising ideas to get you started and sponsor forms. We also provide you with a running vest for use on the race day itself. And if you have your own place in any run do let us know and we'll send you a fundraising pack and running vest too.

The **Albert Bartlett Edinburgh Marathon** on 31 May is a fantastic marathon following a spectacular route through the heart of Edinburgh. You can enter as a relay team of 4 if the full 26 miles is a bit much! You can also make a team of 3 to take part in the **Mazda London Triathlon** with each of you doing one discipline each. Taking place on 1 and 2 August this event is



perfect for beginners and experienced triathletes alike, with Super Sprint, Sprint and Olympic distance categories.

The **Great North Run** is filling up fast, so if you wish to take part in Britain's biggest half marathon, don't delay and get in touch.

Event Calendar 2009

Bupa London 10,000	25 May 2009
Edinburgh Marathon	31 May 2009
British 10K London Run	12 Jul 2009
London Triathlon	1 & 2 Aug 2009
Adidas Women's 5K	6 Sep 2009
Great North Run	20 Sep 2009
Great South Run	25 Oct 2009
Big Fun Run 5K series	Various Aug-Oct

For more information and entry details phone the office, email jo@eruk.org.uk or look at the sporting events page on our website.

football match for Jane Quinn and Natalie Walmsley • Sophie Navro, William Burke and the Wackett family and friends for the Epsom Downs Dash, Fi's Evening and Chobham traders' Christmas shopping evening for Fiona Wackett

and those celebrating a special birthday or anniversary:

Ella Gough, Catriona Davidson, Natasha Hill and Lauren Bradley (16), Jacqueline Barr (50), Paul Hutchinson (60), and Mr & Mrs L Dalmon, Mr & Mrs R Elkerton and Mr & Mrs P Webster (golden wedding).

New memorial funds have been set up for:

Amy Cassidy, David Jordan, Lucie Norman, Alex Shaylor and Jean Waind

Donations have been received in memory of:

Julia Alder, Katie Almond, Dan Amy, Caris Aparicio, Mr Archibald, Aaron Ashworth, Vicki Attwood, Peter Barber, Michael Bareham, Samantha Barrett, Andrew Bettelley, Jonathan Bevan, Betty Billing, Jason Biriny, Arthur Boggis, Jordan Boyce, Edward Bradford, Joan Brailsford, Dorothy Buckless, Alexander Buckman-Drage, Zara May Butler, Robert Camm, Jamie Chivers, Sheila Clark, Edna Collings, Rebecca Collins, Daniel Cowell, Stella Cox, Jade Cronshaw, Tamsin Cummings, Alan Daniels, M G Davey, Kevin Davies, Scott Dewick, Svetlana Dmitrijeva, Martin Dodd, Jason Dover, Kathryn Fazackerley, James Flaherty, Charlotte Fletcher, Sharon Golledge, Kasia Gonzalez, Thomas Green, Vickers Gregory, Barbara Hall, Scott Hamill, Jeffrey Harrison, Albert Hawkins, Derek Hayes, Harold Hayes, John Heron, Yvonne Igoe, Catherine Jarvis, Stephen Jarvis, John Jenkins, Cissie Johnson, David Jones, Pascal Kahan, Enid Kaye, Sam Kent, David Kenworthy, Elizabeth Kidd, Tania Knight, Su Korb, Stephen Lang, Vera Lav, Irene Little, Dale Lockwood, John Manning, Nicola Marland, Matthew McGowan, John McHale, Ellen Mezzetti, John Stuart Mills, Rebecca Milsom, Sara Jane Monk, John Morton, Carl Newell-Hill, Maureen Noblett, Lucie Norman, Mary Owens, Catharine Parker, Florence Parsons, W D Parsons, Robert Pearson, Matthew Peckett, Samantha Pennicott, Colin Perry, Netta Philpott, Daniel Poole, Neil Price, Theresa Prime, Jane Quinn, Helen Richardson, Nicola Rolt, Edward Rose, Mrs E Rourke, Peter Rowles, Stephen Royle, Toni Marie Scanlon, David Scourse, Brian Sealy, Lesley Seddon, Adam Shackelford, Doris Sharples, Jill Sloan, Pat Sloan, Toby Smith, Tony Smith, Ann Spurr, Kathryn Stallard, Peter Stephen, Mrs S Stockdale, Frederick Stubberfield, Jennifer Sykes, Karol Szymaniak, Ian Thompson, Kevin Thompson, Doris Tolhurst, Mark Tomlin, Sarah Torrens, Ann Tucker, Peter Tulett, Mary Twigley, Julia Tyson, Jonathan Vaughan, Fiona Wackett, Mark Sanderson Walker, Evelyn Walker, Natalie Walmsley, Margaret Ward, George Warminiec, Simon Warwood, Lady Valerie Webster, Brett Whiting, Derek Williams, Stephen Williamson, Beryl Wright, Philip Wynne, Jacqueline Yates, Jamie Young,

and bequests received from:

Martyn Crowther, Lord Hastings, Ivy Judge, Hazel Lacey, Patrick Oakley, Nora Profit and Dorothy Richmond Smith.

Our thanks go to all who have chosen to remember their loved ones by supporting our research.

Thanks to all our supporters

We thank all our supporters for their generous support through personal donations and fundraising events, including:

Fran Lohman for a sponsored horse ride • Graham Rolt for the Pathfinder Trek • Ian Rice for a trek in Iceland • Holy Trinity Church, Rothwell charity of the month • Limpsfield Chart Golf Club for the Lady Captain's benefit year • Document Services, Lloyds TSB, Brighton for dress down days • Premier Farnell UK for a golf day • Worcester College JCR charity of the term

those supporting memorial funds:

Jerman family and Nikki Gates for a dinner and prize draw for Vicki Attwood • Bettelley family for Christmas events and lunches for Andrew Bettelley • Legal Services Dept, Plymouth City Council for dress down days, cake and book sale for Becky Collins • Longridge Youth Centre pantomime and the Ollie and Jade committee for Jade Cronshaw • Giles Cummings for an event and Karen Carpenter for a sponsored walk and Christmas party for Tamsin Cummings • Fletcher family and friends for a charity evening for Charlotte Fletcher • Gonzalez family and Yvonne Kenton for a swimathon for Kasia Gonzalez • S.T.A.B.L.E. for events for Carl Newell-Hill • Stan Quinn, Helen Lamb and committee for a Blackpool FC Legends

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