

focus



Epilepsy Research UK Newsletter

Spring 2008

Epilepsy Research UK officially launched

On 28th November 2007, Epilepsy Research UK was officially launched at a reception at the Palace of Westminster. The reception was attended by parliamentarians, researchers and supporters of the charity.

Andrew Lansley CBE MP, the Shadow Health Minister (pictured top right with Professor Helen Cross), very kindly hosted the event and spoke about how the new charity was, "already creating a much better profile for epilepsy research."

Our trustee, the Rt Hon David Cameron MP (below), also spoke, describing his own experience of epilepsy research – being caught on camera with his feet up, reading a copy



of The Sun, whilst his son underwent 24-hour EEG video telemetry at Great Ormond Street. He went on to describe the work of the charity as "vital".

Actor Sam Riley (right), described how he'd prepared for his role of Ian Curtis,

lead singer of 80s band Joy Division, in the film *Control*, an integral part of which was the portrayal of Ian's epilepsy. Sam said, "I was physically exhausted just pretending to do it [have a seizure] for an afternoon. It's impossible for me to understand what it must be like to live with epilepsy."

Two guests who know exactly what living with epilepsy is like were Jane Goldthorpe and her son, Sean (right with Sam Riley). Sean developed epilepsy after a brain haemorrhage at the age of eight, but following brain surgery under the supervision of our Chair, Professor Helen Cross, he has been seizure free since June. Jane said of the operation, "It's changed his life ... what they can do and what they've done for Sean is fantastic."



Professor Helen Cross also spoke about the aims of the new charity saying:

"Epilepsy Research UK is committed to funding and enabling this research in a number of ways.

We are aiming to increase our research funding. In response to our recent call for research proposals we have received applications totalling 5.4 million pounds.

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Research evening lecture

In a new departure for both Epilepsy Research UK and the UK Chapter of the International League Against Epilepsy, a symposium for lay people interested in epilepsy was held at the League's Annual Scientific Meeting, in Southampton in October 2007.

The ILAE conference is the biggest annual epilepsy meeting in the UK. At the evening lecture, doctors and laboratory scientists who specialise in epilepsy were joined for the evening by patients and supporters of Epilepsy Research UK, as our speakers offered a non-technical look at three areas of epilepsy where research is changing treatment and lives.

Inheriting epilepsy

It has been known for a long time that some types of epilepsy can be inherited. However, only about 1% of cases of epilepsy show a clear family inheritance pattern. For around 60% of people with epilepsy, no specific cause for their seizures can currently be found. Research is just beginning to show that genes may play a role in these cases.

Carrie Hammond, a genetic counsellor at Swansea University, who also coordinates the Wales Epilepsy Research Network, described genes as the recipe books for our body. Each gene contains the recipe to make a molecule called a protein. For us to work correctly, every cell in our body depends on thousands of proteins doing their job in the right place at the right time. Tiny mistakes can occur when DNA is

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funding research
changing lives

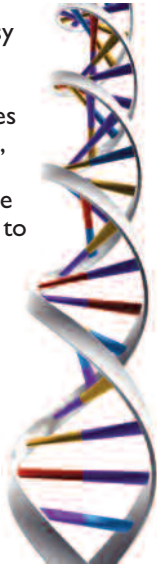


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Research evening lecture

copied when new cells form: sections of gene can be replaced, duplicated or left out altogether (just like misprints in a recipe). These changes can alter the instructions for making a protein, which can mean the protein malfunctions or is missing entirely.

It's now thought that most cases of epilepsy are not caused by a single gene mutation, but instead by changes in a number of genes, each with small and different effects. These gene changes add up to increase a person's likelihood to have seizures, though a person's habits and circumstances (called "environmental factors") can also play a role. Miss Hammond illustrated this interaction between genes and environment by comparing it to driving a car with a number of small faults: one headlight out, windscreen wipers not always working, and one tyre a bit flat. Most of the time the car will run well; in fact it may never have any trouble. But if it starts raining heavily one evening as you're driving down a hilly, windy road, then problems are more likely...



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Developing an anti-epileptic drug

Munir Pirmohamed described the process of developing anti-epileptic drugs and how this has changed over the years.

In the early part of the 20th century, many anti-epileptic drugs were discovered by chance. Sodium valproate, for example, was discovered when it was used to dissolve other test drugs. When all drugs being tested displayed exactly the same strong anti-epileptic action, the researchers realised they'd made a breakthrough, just not the one they were looking for!

Today we know a great deal more about the structure of the brain and how neurones send electrical pulses to each other to communicate. Modern drug development involves designing compounds to interact with specific parts of these very complex processes. For example, carbamazepine changes the electrical behaviour of sodium channels in neurones; vigabatrin

inhibits the action of an enzyme called GABA transaminase in brain cells.

Professor Pirmohamed's research interests focus particularly on adverse drug reactions: how and why they happen, why they vary between patients, and what surveillance systems need to be in place to detect them. He is professor of clinical pharmacology (studying the effects of drugs in people) at the University of Liverpool.

He's also interested in how people's genes affect how they respond to anti-epileptic drugs. This could explain why some people's seizures fail to respond to drugs, and why some people but not others experience very serious side effects. He hopes that research in this field, which is called pharmacogenetics, will eventually allow doctors to predict how a patient will respond to a drug, so as to avoid giving the drug if it won't help or is likely to be dangerous. This would be a major advance for drug therapy in epilepsy.



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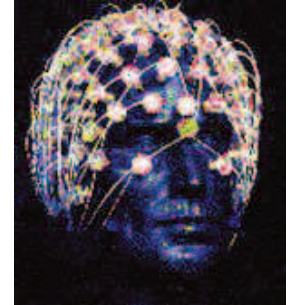
Electrical Impedance Tomography

David Holder described his pursuit of a new imaging method for epilepsy, Electrical Impedance Tomography (EIT). He has been working on this for about 20 years, in a bid to develop a new portable, inexpensive and safe medical imaging method, for imaging brain function in conditions such as epilepsy and stroke.

Professor Holder is professor of biophysics at University College London, and also runs the department at University College Hospital which carries out EEG tests, and also tests on nerve and muscle function.

EIT was originally developed to image the chest via a single ring of electrodes. In order to apply it to epilepsy, Professor Holder had to demonstrate first that it could detect brain function at all; then that it could detect brain function through the skull and scalp using normal EEG electrodes; then that it could make sense of recording in three dimensions (since to record brain activity properly,

electrodes need to be in a hat shape, rather than a single ring); and finally that it can detect and make sense of real seizures. With the newly optimized equipment, a further clinical trial will take place in the near future.



© David Holder

His work has shown that EIT worked in models built of gel, then in animal studies and in preliminary human studies: EIT can definitely detect brain activity. However results on actual seizures have so far been disappointing – the signals detected are too noisy, so the picture of brain activity is too fuzzy. Members of Professor Holder's research team (supported between 2003 and 2007 by a £146,058 grant from Epilepsy Research UK) are currently refining the computing and engineering to reduce the noise and sharpen the focus.

The next lay symposium will be held at the 2008 ILAE meeting in Dundee on 8 July – book your place now!

Professor David Holder has recently secured a grant of £900,000 from the National Institutes of Health in America to fund the development of his innovative imaging technique, Electrical Impedance Tomography. For a scientist based outside the US to receive a grant of this size is extremely rare which clearly demonstrates the quality of his work and the potential it has to dramatically improve epilepsy diagnosis.

New information leaflets

We've updated all our information leaflets and added two new ones, **Epilepsy and Driving**, and an **Epilepsy Checklist**. Download the leaflets from www.epilepsyresearch.org.uk/about_us/leaflets.htm

Epilepsy Research UK's portfolio of grants

Epilepsy Research UK currently has 24 grants ongoing, which represents a total of £1.25 million committed to epilepsy research.

The average grant is for £51,600, lasting a fraction over two years. Only one of our ongoing grants is a fellowship: all the others are for projects. Our grants fund sixteen people to work full time in epilepsy research, and we are also part-funding the salaries of a further four people.

Nine of our grants are funding basic laboratory research, finding out how specific features of the brain work, how brains which are prone to seizures are different from brains which aren't, and how drugs interact with the brain.

We are funding twelve clinical research



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projects, investigating the effects of treatments for epilepsy in patients (both effectiveness and safety), and the features of specific types of epilepsy. Two of these are looking at epilepsy in children, and five are looking at the genes behind specific aspects of epilepsy.

Finally we have two grants looking at qualitative issues: finding out what the psychological and social effects of epilepsy are, and how treatment can affect this.

All our grants are listed on our website at www.epilepsyresearch.org.uk/about_research/grantsindex.htm

All our grants are selected via our annual open competition. This is adjudicated by our Scientific Advisory Committee (SAC), composed of eight epilepsy experts and two lay people with personal experience of epilepsy. This year's competition attracted 56 applications, the largest number we've ever received, totalling £5.4 million. After an initial selection round in November, we consult independent experts worldwide on the quality of each application. Our SAC meets in mid-March to pick the best for funding.

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Epilepsy Research UK officially launched

"Because we are scrupulous in what we fund in terms of good science, innovation, achievable goals and value for money we would probably not support all the applications, but we would like to be in the position to consider it!

We want to encourage collaboration amongst researchers that will enable them to access increased levels of statutory funding for their work. To this end we will be working to establish a nationwide epilepsy research network that would be best placed to benefit from recent developments in NHS funding.

We also want to encourage talented scientists and clinicians to pursue a career in epilepsy research. To achieve this, we are launching a fellowship award of £200,000 to bring new people into the field.

To date, epilepsy research has been severely underfunded to the detriment of the hundreds of thousands of people affected by the condition. I sincerely believe that Epilepsy Research UK has the capacity to change this and I would like you to join me in raising your glasses to the future success of Epilepsy Research UK."

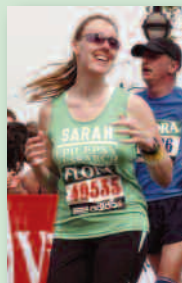
A film of the launch event can be viewed at www.epilepsyresearch.org.uk.

Fundraising news Sporting events

Our congratulations and thanks to the 68 dedicated runners who trained so hard to represent the charity last autumn in the Great North Run, Great South Run and Junior Great South Run and to the individual supporters who ran in the London Duathlon, Sedgfield Serpentine Race, Glasgow Big Fun Run, Mablethorpe 10K, Richmond Castle 10K, Bristol Half Marathon and the Dublin and Wolverhampton marathons.

Join our team

For details of all our 2008 sporting events and overseas challenges please see the **Join our team!** leaflet enclosed with this newsletter.



Trolley tokens

Never be without a coin for your trolley or locker again! We now have Epilepsy Research UK trolley/locker tokens available for a £1 donation each. If you can sell these to your friends or place a box at your local sports centre, please call the office to arrange a supply.

Shop or surf online and support our research!

It's easy to fundraise online for Epilepsy Research UK. You can

- shop online with major retailers via **easyfundraising.co.uk**. Up to 15% from every purchase is donated to the charity of your choice
- search the internet through **everyclick.com**, the search engine and shopping portal that gives 50% of its revenue to charity
- sell items on **eBay.co.uk** and donate all or part of the proceeds to us
- set up a wish list for a wedding, birthday or anniversary on **whatidlove.co.uk** and include a donation to us

easyfundraising
org.uk



eBay
co.uk

whatidlove

Fundraising groups

Would you be interested in being part of a regional fundraising group and helping to organise events with other Epilepsy Research UK supporters? If you would like to help establish or be involved with a fundraising group in your area, please contact Jo Stebbing at the Epilepsy Research UK office.

Focus on fundraisers

When Will Prowse agreed to guide his wife and two of her sisters up the highest mountains of Scotland, England and Wales there was never any question in their minds as to who would benefit. Heather Prowse, Cyn Porter and Rachel Scoble tell us about their **Three Sisters Three Peaks Challenge** for Epilepsy Research UK.

We are actually a family of 4 girls and our eldest sister's son has suffered with epilepsy since the age of 3. Due to episodes of status epilepticus this has severely affected his life and that of those close to him. We felt that Epilepsy Research UK's sole focus on epilepsy made it a worthy recipient for any money donated and since we completed our event it has been great to see the range of projects the charity is supporting.

Two of us had never climbed a mountain before, but with the assistance of our guide Will and driver Andy (and of course some training beforehand) we set out to climb Ben Nevis, Scafell Pike and Snowdon in under 24 hours in the hope of raising £1,000 for epilepsy research. Little did we expect that in May we would be battling through high winds, snow and torrential rain along the way! Ben Nevis and Scafell Pike were duly conquered and we reached the Llanberis Pass still with a chance of finishing in time. With no time to stop on the summit of Snowdon for the champagne we'd promised ourselves, we set off down and ended at the bottom together with just 7 minutes to spare. Amid a few tears of relief we opened the champagne and began our celebrations!

Heather, Cyn and Rachel doubled their original fundraising target and raised £2,128.77 for Epilepsy Research UK. Our thanks go to all the team for their spirited determination to complete the challenge and to their sponsors for such generous support.



Thanks to all our supporters

We thank all our supporters for their generous personal donations and for their enterprise in raising funds for research, including:

Farnell in One for their highly successful golf day ● Zoe Wilcox who took the Inca Trail Trek to Machu Picchu ● Lindsay Attfield, parachute jump ● Gordon Spence, Matthew Cherry and Jim Cochrane of the Todhill Country Centre, sponsored cycling trip to the Galloway Forest ● Jo Christoffersen and friends in Achiltibuie, sale of textiles and lunches ● Cathy Gilbert for a concert at St Peter's Church ● Simon Ingham, sponsored head shave ● Mr Ducatel for a raffle ● Brenda Horne, tombola and church choir's sale of CD ● Leslie Williams for a sponsored walk ● the Rotary Club of Chipping Campden, Welsh choir concert and Tree of Light ● Broadwater School ● Chesham High School ● Mountain Lane Primary School ● White Styles Middle School

those supporting memorial funds:

John and Nancy Bettelley, drinks parties and a Christmas raffle for Andrew Bettelley ● Kelsham Buckman-Drage, parachute jump for Alexander Buckman-Drage ● Jonathan Moody and friends for a James Bond evening for Jamie Chivers ● employees of Plymouth City Council, Swimathon for Rebecca Collins ● Giles Cummings and friends for organising a football tournament, Karen Carpenter and family for a beach walk and party in Oman, and Sacha and Jamie Pearson for their Coast to Coast walk for Tamsin Cummings ● Darren Wells and Astute for their Party in the Park, and Walton Women's Institute for a tea party for Sharon Golledge ● employees of Keystone Distribution who keep filling their swear box for Sam Kent ● Hadley Connor, Rob & Liz Goodliffe, John O'Halloran, Keith Wisdom, Barry Foulser and Stuart McElligott who completed the Yorkshire Three Peaks for Ellen Mezzetti ● students at St John's RC School, Bishop Auckland for a concert in memory of Pako Moholo

and those celebrating a special birthday or anniversary with donations:

Tim Coxon (50), Mrs Whiting (60), Caryl Fuchs (70), and Mr and Mrs Wheal (Ruby Wedding).

In memoriam donations and bequests

Since the last newsletter new memorial funds have been set up in memory of Philomena Cleland, Pako Moholo and Tony Smith.

Donations have been received in memory of:

Victoria Attwood, Elsa Bent, Andrew Bettelley, Jonathan Bevan, Maud Boden, Ian Borrino, Paul Bourn, Joan Brailsford, Andrew Bramall, Timothy Brown, Dorothy Buckless, Alexander Buckman-Drage, Jamie Chivers, Brian Clarke, Edna Collings, Rebecca Collins, Mark Collins, sister of Joyce Craig, Jade Cronshaw, Tamsin Cummings, Jim Davey, Edward Daw, Geoffrey Day, Margaret Dibble, Patricia Dimmick, Ray Dowling, Nick Drake, David Eaton, Kevan Elliman, Clive Ellis, Sheila Fitzgerzald, Charlotte Fletcher, Daniel Flynn, Dawn Funnell, Alistair Gibson, Carlo Giuliani, Sharon Golledge, Kasia Gonzalez, Hilda Goodwin, Brian Harvey, Edward Hazell, David Herd, Agnes Hill, Douglas Jackson, Catherine Jarvis, Rachel Jones, Jacqueline Jones, Walter Kent, Sam Kent, Tania Knight, Stephen Lang, Brian Lindo, Gareth Lloyd-Evans, John Lynn, Graeme MacDonald, Bernard Magee, Anthony Marfleet, Nicola Marland, Lauren Mayes, Kirsty McQueen, Ellen Mezzetti, Gemma Morgan, John Morton, Carl Newell-Hill, Margaret Newman, Margaret Norris, Susan Pady, Pauline Payne, Samantha Pennicott, Jane Quinn, Helen Richardson, Mr Ridler, Ben Roberts, Colin Roberts, Mark Sanderson Walker, David Scourse, Steven Shaw, John Shepherd, Jill Sloan, Pat Sloan, Alexander Smith, Henry Smith, Jennifer Sykes, Sarah Torrens, Samuel Walker, Natalie Walmsley, Brett Whiting, Graham Whitmore, Albert Wilkinson, Evan Williams, Beryl Wright.

We are grateful to have received bequests from:

Peggy Mary Clark, Peter John King, Olive Rosson, Rachel Jean Rush, Mrs Styles, Elizabeth Wilson, Gordon Yeatman.

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

Epilepsy Research UK

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