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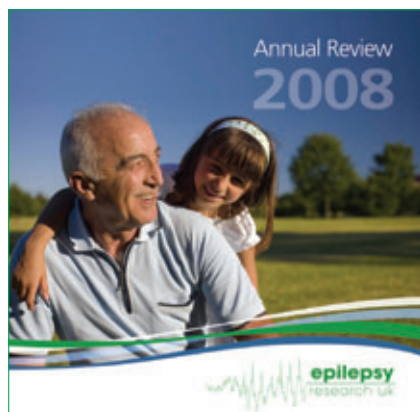
Epilepsy Research UK Newsletter

Autumn 2008

The year in review

We have recently published our 2008 Annual Review that describes our activity during the financial year ending 31st March 2008. The review outlines the nine new research projects that we commissioned in March. Each one, we hope, will advance our understanding of the causes of epilepsy and how best to treat the condition.

Epilepsy Research UK's first year, following the merger of the Epilepsy Research Foundation and the Fund for



Epilepsy, was a great success. Income for the year was over £1.3 million, a 57% increase on the combined income of the two charities prior to merger. This is entirely due to the generosity of supporters such as yourselves.

Despite the deteriorating economic climate, donations in this financial year have to date exceeded those of last year, so we are hopeful that with your continued support we will continue to make great strides in funding innovative research into the prevention of epilepsy.

If you would like to receive a copy of the annual review, please contact Shona Scott on 020 8995 4781.

Research Evening Lecture

This year Epilepsy Research UK again held its evening lay symposium at the UK Chapter of the International League Against Epilepsy (ILAE) Annual Scientific Meeting, on 9 July, in Dundee.

Epilepsy Research UK's Chair of Trustees, Professor Helen Cross, of The Institute of Child Health, University College London, gave a talk on *Using the ketogenic diet to treat epilepsy in children* (outlined below) and Professor Gus Baker of the Department of Neurological Sciences, University of Liverpool talked about *Understanding the impact of epilepsy on psychological functioning*.

The ketogenic diet

The ketogenic diet is one that is high in fat and low in both carbohydrate and protein, and it has been used to treat seizures in children with epilepsy for nearly 90 years.

In May 2008, the results of the first ever randomised controlled trial of the ketogenic diet were published in the *Lancet Neurology*. The trial involved 145 children aged between 2 and 16, divided into two groups – one of which started the diet three months later than the other. For that period, the delayed group was the control group. The children all had active epilepsy, with seizures at least once a day, and had not responded to at least two anti-epileptic drugs (AEDs). The children in both groups kept on taking any AEDs they had been on before the study.

Continued on page 3

Epilepsy Research UK Expert International Workshop

The psychological and social consequences of epilepsy

For approximately 30% of people with epilepsy, their condition cannot be controlled with medication, and so they must cope with continued seizures.

Seizures make life extremely difficult to deal with, firstly because they are unpredictable and must always be planned for, and secondly because they cause a loss of self control. This is something that human beings find particularly distressing, and is probably the reason why epilepsy is so heavily stigmatised.

Studies have shown that depression and anxiety are more common among people with epilepsy than in the average population, and that both unemployment and under-employment are more common also. Furthermore, people with epilepsy

are less likely to get married and have children than those without.

Quantifying the impact of epilepsy on a person's life is a complex task, because depending on a person's age, the nature of their daily activities and encounters will be different. For example, factors that affect children such as learning how to make friends at school and working towards exams won't be the same as those that affect an adult who is working or job-seeking.

On 6 to 8 April 2008, sixty experts and students of the psychological and social consequences of epilepsy met in St Catherine's College, Oxford, for the Seventh Epilepsy Research UK Expert International Workshop.

Continued on page 2

**funding research
changing lives**

Continued from page 1

International Workshop



For two days the participants discussed the role of epilepsy in causing or worsening psychological conditions such as depression, anxiety, irritability and memory problems, and social issues like employment and the importance of strong and supportive social networks.

The presentations and discussions explored how these factors vary depending on the age and background of the person with epilepsy, the type of epilepsy they have, and the treatment they are receiving. The workshop also covered how doctors can help patients, and how to design good research projects to investigate these issues.

The workshop was chaired by Professor Gus Baker, of the University of Liverpool, Professor Mike Kerr, of the Welsh Centre for Learning Disabilities in Cardiff, who is a member of Epilepsy Research UK's Scientific Advisory Committee (SAC), and Dr Richard Appleton of the Royal Liverpool Children's Hospital, who chairs the SAC.

Professor Matti Sillanpää of the University of Turku, Finland, described the substantial impact that epilepsy has on a child's life. Even children with uncomplicated epilepsy have problems in learning, behaviour, communication, personal care and manual skills. Many are dependent on others for their physical needs, and find it difficult to make friends.

Epilepsy affects men and women differently. However both sexes are likely to have fewer children than might be expected. Having seizures can decrease sexual drive, as can some anti-epileptic drugs (AEDs). Drugs can also cause some metabolic and cosmetic side effects (hair growth, weight gain or loss). Both men and women with epilepsy report feeling less confident about providing for their family and caring for their children because of their epilepsy.

Professor Page Pennell of Emory University School of Medicine, Atlanta, USA, also looked at the considerable

body of data on the risks associated with pregnancy. Taking AEDs during pregnancy increases the likelihood of either miscarriage or having a baby with a serious disability. The risk depends upon which drug(s) the mother is taking and at what dose(s). The greatest concern surrounds sodium valproate, which leads to a dilemma if the woman with epilepsy is well-controlled on this drug.

A survey of the healthcare and research needs for adults with epilepsy worldwide was provided by Dr E S Krishnamoorthy, of the Institute of Neurological Sciences, Chennai, India. He stated that epilepsy is clearly a disabling illness from a psychological and social perspective. People with epilepsy are likely to be significantly affected by having seizures, and to have a poorer quality of life than other people who are like them in all other respects in the communities they live in. They have on average lower educational attainment, are less likely to be employed or to be married. They are more likely to suffer from psychosis, depression and other neuropsychiatric disorders, and are more likely to perceive stigma from others.

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Dr Krishnamoorthy made a series of detailed suggestions for how doctors and nurses should be trained and organised in GP surgeries, at hospitals and in specialist epilepsy clinics, both in developed countries and in the developing world. He stressed that the person with epilepsy should remain the focus of all decisions, and should have a say in what is considered to be good practice in the clinic and in research. He also argued that research priorities should focus more on the questions people with epilepsy would like answered.

Dr Peter Martin of the Séguin-Clinic for Persons with Severe Intellectual Disability, part of the Epilepsy Centre in Kork, Germany, looked at the special issues affecting people with epilepsy who also have an intellectual disability. This is a difficult group to investigate as many cannot easily communicate their feelings or needs. The extent to which epilepsy affects them depends on how severe and frequent their seizures are, at what age they started, how severely their intellectual ability is affected, the treatments they are receiving, the support available to them and how their

psychological state and behaviours are affected by all the above. Also important is how much the people who look after them know about epilepsy and can adapt to cope with it. Much research is still needed in this group of people to better characterise their psychological response to epilepsy and understand the long and short-term effects of treatment.

The proceedings of the workshop will be published in the journal *Epilepsy & Behavior* in mid-2009.

Encouraging young researchers: The Celine Newman prize



At the ILAE UK Chapter conference the Epilepsy Research UK Basic Science Symposium, generously supported by ICAP, gives promising young researchers an opportunity to present their work. The Celine Newman prize is awarded for the best presentation as judged by a panel comprising members of the ILAE Council and the Epilepsy Research UK Scientific Advisory Committee.

Our congratulations to Dr Murray Herd (above) of the University of Dundee who was the 2008 Celine Newman prize winner at the Basic Science Symposium.

Dr Herd and his team have been examining nerve pathways between the cortex of the brain and the thalamus, which are vital in the production of normal brain rhythms. If these are disturbed, absence epilepsy can result. Dr Herd and his team have found the identity of the neuronal receptors that are crucial in maintaining the brain's normal rhythms. This exciting development means that more targeted drugs for absence epilepsy, which enhance the activity of these receptors, can be developed in the future.

Continued from page 1

Research Evening Lecture

At the end of the three month comparison period, the children on the ketogenic diet had on average a 38% drop in seizure frequency, whereas seizure frequency in the control group had increased. In over a third of children on the diet, seizure frequency had

halved. This was the case in only 6% of the control group. Seven percent of children in the diet group had more than a 90% fall in seizure frequency.

Side effects of the diet included vomiting, diarrhoea, constipation and feeling hungry, most of which could be treated by adjusting the diet. The diet didn't suit everybody, however, and six children dropped out.

This is the first trial that clearly shows that the ketogenic diet is a better treatment option for children with drug-resistant epilepsy than no change. The rates of response to the diet are similar to those seen in trials of new AEDs. The diet worked equally well in all types of epilepsy.

Videos of the lectures can be viewed at: www.epilepsyresearch.org.uk/about_epilepsy/videos.htm

Focus on fundraisers

Parachuting

Gemma Brierley, inspired by her sister's life-changing operation at Great Ormond Street Hospital, tells us about her tandem skydive for epilepsy research.

"When my sister Rebecca was born she was the most beautiful baby I had ever seen. I knew then that I would do anything for her, but little did I know that 16 years later it would involve me jumping out of a plane!

My sanity did cross my mind on the 12 minute journey to 14,000ft and as the plane's door slid open the full horror of what I'd agreed to do hit me. My eyes began to water and Tony (my instructor) began to shuffle me toward the door. "Feet out!". My heart was in my mouth and I wanted to say, "no way", but having to return sponsor money was not an option! I clung to Tony for dear life as we rocked out of the plane at 180mph. After I had the courage to open my eyes the most fantastic view greeted me. I could see for miles, and to be on top of the clouds not behind glass was amazing! Once the parachute opened Tony did a few tricks and even let me take control for a while. After a perfect landing by Tony I gave him a massive hug – and was hooked. I signed up immediately to learn how to do it myself.

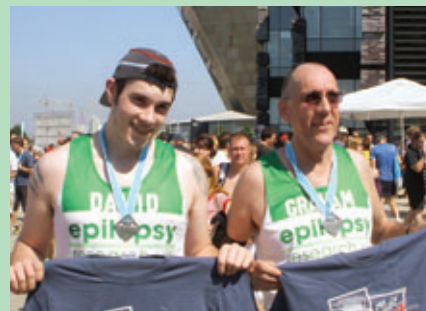
From someone that was terrified of heights to someone that has now done 6 solo jumps I have to say a massive "Thank you!" to both Epilepsy Research UK and Black Knights Parachute Centre for one of the best experiences of my life."

Well done to Gemma for her courage in skydiving and for raising over £1,378.

BUPA Great Wales Run

On a hot July Sunday morning in Cardiff Bay, Graham Lewis and his son David took part in the Great Wales 10K Run to raise funds for Epilepsy Research UK.

Graham's brother was diagnosed with epilepsy when he was a teenager and took medication throughout his life to control it. Unfortunately, he died in an accident exactly a year ago.



This was Graham's first race and opened his eyes to a number of things. Firstly how generous people can be, and secondly how easy it was to start running. *"Even though I was going to the gym at least three times a week, pounding the streets is totally different and much better. If I can do it, so can anyone else!"*

Both Graham and David completed the course in one hour and three minutes, and raised £950 for epilepsy research.



Art for charity

Penn Morcom-Webb, a partially sighted man, held an art exhibition of his works to raise funds for Epilepsy Research UK in memory of Simon Beard.



Ben Nevis

Eddie Kuprewicz, Dennis and Chris Stocks climbed Ben Nevis on 21 June 2008 for the Daniel Poole Memorial Fund.

Three Peaks Challenge

An intrepid team of eight supporting the Ellen Mezzetti Memorial Fund took on the Three Peaks Challenge – to climb Ben Nevis, Scafell Pike and Snowdon in under 24 hours – on 21/22 June.

Despite high winds and torrential rain along the way, they somehow found the energy to jog the last 1/2 mile to complete the challenge with just four minutes to spare!

Thanks to Barry Foulser, Keith Wisdom, John Mezzetti, Samantha Hicks, Sharon Jones, Jenny Armstrong, Jeremy Boreham and Matt Copeman and their drivers Alan Lamb and Sharon Grant for raising over £6,000 for Ellen's memorial fund.



Sporting events

It's been a busy summer! We've battled the rain at the British 10K,



the Mazda London Triathlon



and the adidas 5k Women's Challenge!

In all 125 of you took part in these three events which is fantastic support. We've also had runners in the Great Wales Run, the Bupa Great Capital Run, the Great North Swim

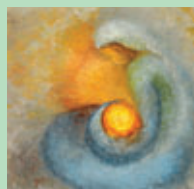


and the Bristol Half Marathon.

Christmas cards

Our Christmas card order form is enclosed. The cards sell fast so order now to avoid disappointment!

All the profits from the sale of our cards go direct to our research so every purchase really does help to make a difference. You can also buy our cards online at www.epilepsyresearch.org.uk Postage & packing is free on all orders of 2 packs or more. For a separate range of corporate cards see www.charitychristmascards.com.



There are many more of you who have been raising sponsorship in your own events, from coast to coast cycle rides across America, sponsored walks, football matches and more! We would like to thank each and every one of you who have taken part in events in support of us this year.

Marathon fever

The Flora London Marathon is our first big event of 2009, taking place on 26 April. The individual ballot has already closed.

If you were successful in the ballot we would love you to run in support of us. If you were unlucky in the ballot or missed entering and would like to be considered for one of our guaranteed entries in the London Marathon please email jo@eruk.org.uk or log onto our website.

It doesn't end there with the Edinburgh Marathon just weeks later on 31 May. This is one of the most spectacular marathons in the world and is a far less crowded race than London's. A beautiful course sees you from Edinburgh out to Musselburgh race course for the finish. Entry is now open for this event. You can enter as an independent runner or relay team of four, or on a guaranteed charity place – the choice is yours.

Running events 2009

April	Flora London Marathon
May	BUPA London 10,000 Great Manchester Run Edinburgh Marathon
July	British 10K London Run
August	London Triathlon
September	adidas 5k Women's Challenge
October	Great North Run Great South Run

Email jo@eruk.org.uk or phone the office for entry details.

Thanks to all our supporters

Our thanks to all our supporters for their generous personal donations and for their enterprise in raising funds for research, including:

Elaine Barrett and Sue Lavers who trekked to Machu Picchu in Peru in memory of Elaine's daughter, Samantha • Tina Cox for a book fair • Andrea Fletcher for her 'Darwin & Friends' race night • Ella Hashemi for her Transamerica cycle ride • Sylvia Lambert for a lunch party • Fiona Middleton-Walker for a fashion luncheon • Edith Simms for a 24 hour fast in memory of her daughter Jill • Rachel Spooner for her school reunion fundraiser • Alistair Thompson for the Ian Thompson memorial football match • Key Equipment Finance for a corporate golf day • Lairdisland School • Wood Green School • Lepton C of E School • Marston Methodist Church.

those supporting memorial funds: Blackheath Tennis and Rugby Club for Andrew Bettelley • Cronshaw family events for Jade • Staff and pupils at St John the Evangelist School for Charlotte Fletcher • Jo Stephens and staff and customers at Sainsbury's supermarket Hereford for Emma Knight Bolton • Jessie Biggs, Lee Cass and Steve Taylor for parachute jumping for Nicola Marland • Staff at Keystone Foods collecting for Sam Kent • Mezzetti and Facey families for their annual family fun day for Ellen Mezzetti.

and those celebrating a special birthday or anniversary:

Mrs Bolt, Mr and Mrs Nash.

In memoriam donations and bequests

Since the last newsletter new memorial funds have been set up in memory of Jason Biriny, Emma Knight Bolton and Fiona Wackett.

Donations have been received in memory of: Hazel Anderson, Charles Ancombe, Samantha Barrett, Andrew Bettelley, Joan Brailsford, Enid Brown, Alexander Buckman-Drage, Danny Burns, June Chamberlain, Jamie Chivers, Alex Clark, Philomena Cleland, Alan Cole, Rebecca Collins, Florence Cooper, Daniel Cowell, Jade Cronshaw, Tamsin Cummings, Kevin Davies, Mrs Daw, Edward Daw, Svetlana Dmitrijeva, Charlotte Fletcher, Michael Goldfinch, Sharon Gollidge, Kasia Gonzalez, Marion Harlow, Andrew Harvey, Martin Hayward, Robert Hill, Mrs J M Hill, Michael Hines, Elaine Howe, Catherine Jarvis, Cissie Johnson, Brigid Keaveney, Antony Kemp, Sam Kent, William Kilby, Stephen Lang, Elizabeth Lazarus, Colin Lock, Amy Mann, Nicola Marland, Ross McAuliffe, Kenneth McWalker, Alexandra Meek, Kathleen Parker, Catharine Parker, Mark Parry, Kenneth Paskin, Matthew Peckett, Daniel Poole, Rev Raymond Porter, Jane Quinn, Irene Redwood, Helen Richardson, David Robb, Helena Robinson, Nicola Rolt, Ray Russell, Leanne Ryan, Mark Sanderson Walker, David Scourse, Jill Sloan, Tony Smith, Kathryn Stallard, Peter Stephen, Sarah Torrens, Ann Tucker, Philip Tucknott, Mark Walker, Annie Warburton, Simon Warwood, Beryl Wright, Jacqui Yates, Jamie Young.

We are grateful to have received bequests from:

Mabel Barrett, Cissie Johnson, G A Mott, J E Selman, Jeanette Wilson.

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