New research, new advances

It is my great pleasure to introduce this latest edition of Focus which features details of the seven new projects we have recently added to our research portfolio.

As always the projects cover a broad range of topics including: the mechanisms that cause SUDEP, side effects of anti-epileptic drugs and the role of stress as a seizure trigger. We are confident that all these projects will make a significant contribution to our understanding of epilepsy.

Making an equally significant contribution to our work are our supporters. On page 5 we feature the adventurous fundraising exploits of Andy Griffiths who has travelled the world to fundraise for us, but equally important and just as appreciated are all the people who have supported us closer to home. Many took up the challenge of organising a fundraising event during National Epilepsy Week, others have responded to our SayYes campaign and set up a monthly direct debit. However you choose to support our work, your generosity is always gratefully received.

At our recent reception at Westminster, kindly hosted by Oliver Letwin MP, there was a real sense of shared commitment between our researchers and supporters to make the advances that will change the lives of people with epilepsy. We feel incredibly privileged to be part of this team which has the potential to make a real difference.

Leigh Slocombe, Chief Executive

**NEW RESEARCH, NEW ADVANCES**

**Cutting-edge techniques to explore brain cell activity in epilepsy**

**DR ROB WYKES**
UNIVERSITY COLLEGE LONDON

Focal neocortical epilepsy (in which seizures arise in a specific part of the neocortex – the brain’s folded surface) is often resistant to anti-epileptic drugs, and there is an urgent need for new treatment strategies. Dr Rob Wykes, at University College London, has recently developed an animal model of chronic focal neocortical epilepsy, which has become a powerful tool for investigating seizure mechanisms and evaluating novel treatment options. Previous research into focal neocortical epilepsy has largely focused on acute induced seizures; however it is clear that in chronic epilepsy there are both pro-epileptic and anti-epileptic changes to neuronal networks. Studying a chronic model of epilepsy will, therefore, undoubtedly increase our understanding of this condition.

Recent technical advances in microscopy mean that it is now possible to capture, in real time and exquisite detail, the activity of large populations of neurons whilst animals are awake. However, this technology has not yet been used in the field of epilepsy research. Dr Wykes has been awarded a fellowship grant of £211,516, in which he will apply these cutting-edge techniques to his model of chronic neocortical epilepsy. His main focus will be on how brain cells behave just before a seizure, and what happens to their activity when a seizure is taking place.

The findings from this study will potentially lead to the identification and development of new therapies that prevent seizures from starting or spreading.

**Why does SUDEP happen and can it be prevented?**

**PROFESSOR JOHN JEFFERYS**
UNIVERSITY OF OXFORD

Sudden unexpected death in epilepsy (SUDEP) is defined as the sudden death of a person with epilepsy, which cannot be attributed to any cause such as trauma or drowning, and for which no toxicological or anatomical cause is found. The underlying mechanisms of SUDEP are not fully understood, but with more than 500 people in the UK dying in this way each year, it is a serious cause for concern.

**RESEARCH GRANTS AWARDED IN 2014**

**Epilepsy Research UK 2014 grant awardees: Dr Rob Wykes, Dr Rachel McNamara, Prof Mark Richardson, Dr Rachel Charlton, Prof Stafford Lightman, Prof John Jefferys, Mrs Gina Parker**

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Initial experiments have revealed that significant changes in heart function accompany seizure activity, and that the heart may even stop for several seconds. Professor Jefferys has now been awarded £149,752 to investigate: how breathing and heart function are affected by seizures and other changes in brain waves related to epilepsy; whether repeated seizures cause structural damage to the heart, and whether drugs can control seizure-related changes in heart and lung function. This research will provide direct evidence on likely causes of SUDEP, and it may ultimately help in the identification of preventative strategies.

Professor Jefferys’ project has been supported by our memorial funds. We would like to thank all our memorial fund supporters for their great generosity over the past year.

Identifying side effects of epilepsy drug treatment in people with learning disability

Dr Rachel Charlton
University of Bath

For women with epilepsy pregnancy requires very careful planning, because several anti-epileptic drugs (AEDs) have been shown to increase the chance of birth defects in the unborn child. Exposure to certain AEDs before birth can also have effects upon a child’s behaviour and development, but the nature of these is not fully understood and further research is needed.

Traditional methods for evaluating behaviour and development (i.e. face-to-face interviews) require a lot of work and they are very expensive. In recent years, databases that contain routinely collected electronic patient medical records have been increasingly used to study these effects. However, whilst this approach offers many advantages, including lower cost and access to larger numbers of exposed children, it is not clear whether it is a reliable way of detecting developmental problems. This is important to know, because if risks are overestimated, an AED that is in fact safe and effective may not be recommended by doctors; but if they are underestimated, doctors may recommend an AED and inadvertently cause harm.

Dr Rachel Charlton, at the University of Bath, and colleagues in Bath, Birmingham, Liverpool, Manchester, Newcastle and Cork, have been awarded a project grant of £98,160, in which they will investigate other methods using routinely collected healthcare data as reliable as direct clinical observation for studying the effects of AEDs on child development. During the study, the team will take existing anonymised electronic data from a database of general practice (GP) records called the Clinical Practice Research Datalink, and they will use it to estimate the risk of neurodevelopmental problems following exposure to different AEDs in the womb. They will then compare their results to those from a previous study led by researchers in Liverpool, which used traditional methods.

This project will help doctors to provide women who have epilepsy with the most reliable and accurate information about their treatment options during pregnancy. It will also serve as a guide to researchers who are planning to explore the neurodevelopmental effects of AEDs in the future.

The link between stress and seizures

Professor Stafford Lightman
University of Bristol

People with epilepsy frequently report emotional stress in the lead-up to a seizure; but although the association between stress and seizures is well recognised, the mechanisms for this are still not understood.

The steroid hormone cortisol is secreted by the body in spurts over the course of the day, and its levels increase dramatically during stress. Cortisol is known to have major effects on both neuronal activity and on the ways that brain cells communicate, so it could plausibly play a role in seizures. Professor Stafford Lightman at the University of Bristol, and colleagues in Bristol and Exeter,
A potential new treatment for childhood epilepsy

MRS GINA PARKER
BIRMINGHAM CHILDREN’S HOSPITAL NHS TRUST

EEG-biofeedback is a non-invasive learning strategy that can enable a person to alter his/her brain wave activity. It has already been shown to be a safe and effective therapeutic option for some adults with epilepsy, but as yet there are no data available for children. Mrs Gina Parker and colleagues at Birmingham Children’s Hospital NHS Trust have been awarded £9,965 with which they will assess the feasibility of using EEG-biofeedback as a therapeutic tool in children with benign childhood epilepsy with centro-temporal spikes (BCECTS).

BCECTS (or Rolandic epilepsy) is the most common childhood epilepsy syndrome, but because seizures often occur at night, and are usually ‘outgrown’ in adolescence, it is often left untreated. Research now suggests that disruption to sleep during BCECTS can cause memory problems, and so the need to treat is being reviewed. Many parents are reluctant to have their child take anti-epileptic drugs (which can have pronounced side effects), especially when their seizures don’t obviously affect their daily life, and so a non-invasive approach would be very welcome.

During the study the team will recruit children with a diagnosis of BCECTS, who are not being prescribed any medication. Each child will be asked to attend a neurology appointment, where they will undergo a baseline 24-hour EEG assessment. Their EEG activity will be analysed on-line, and it will then be used to drive a video game displayed on a screen. The child will then be asked to ‘work the video with their brain’; and the system will be set up so that the video game moves faster when the brain is relaxed. In this way the child will be trained to maintain a state of brain relaxation (less prone to seizures), and they will be able to see when they are achieving this state.

The children will attend regular 30-minute training sessions for six weeks, and they will receive video feedback every week. The researchers will compare the ‘current’ EEG to the baseline 24-hour EEG at specific time points during training, in order to measure a child’s progress. They will also compare the frequency of EEG abnormalities during the 24-hour recording at baseline and at the end of the study, to see if there has been any reduction.

If successful, this pilot grant will hopefully prompt larger studies into EEG-biofeedback as a new, non-invasive treatment for BCECTS.

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TAKING PART IN RESEARCH

We often receive enquiries from people wishing to take part in research projects relating to epilepsy. Epilepsy Research UK does not run any research trials itself. However, if you would like to contribute to research in this way, there are various avenues you can explore to see if there is an opportunity appropriate for you.

Taking part in a clinical research trial

Clinical research investigates new treatments in human patients, particularly their efficacy and safety.

Qualitative research

This kind of research looks at issues affecting patients, for example how a condition affects them psychologically or their experience of the care they have received.

Details of research trials currently recruiting in the UK can be found on the NHS Choices website, www.nhs.uk/conditions/epilepsy/pages/clinical-trials.aspx, and on the UK Clinical Trials Gateway, www.ukctg.nihr.ac.uk.

If you wish to join a trial you should discuss this with your doctor first before contacting the trial; some trials may require a doctor’s referral. The charity Epilepsy Action also lists research studies recruiting patients or their families on its website.

Helping in basic research

Basic researchers often need human tissue for their investigations so choosing to donate tissue is a valuable way of making a contribution to research. If you have surgery for your epilepsy, you may be asked if you would want to consent to the doctors taking a sample of your tissue for research purposes.

People can also now donate to a dedicated central epilepsy brain and tissue bank, the Epilepsy Society Brain and Tissue Bank, a collaborative project between Epilepsy Society and University College London (UCL), based at the UCL Institute of Neurology. For more information about becoming a donor email epilepsysbrainbank@ucl.ac.uk or phone 020 3448 4009.

Before registering your wishes and giving your consent as a donor you may wish to discuss the issues with your family and doctors, and should inform them of any decision you take.

You can read more about current issues in epilepsy research in the research section on our website, www.epilepsysresearch.org.uk

Reception at the House of Commons

The Rt Hon Oliver Letwin MP kindly hosted an evening reception for Epilepsy Research UK at the House of Commons in June. The occasion gave ERUK staff and trustees a welcome opportunity to thank some of the charity’s supporters in person, and a chance for those supporters to meet ERUK grantholders and find out more about the research they have helped to fund. Mr Letwin welcomed the guests and spoke of his knowledge of ERUK’s excellent work through his constituent Alex Woodward, and of his pleasure at being able to help the charity.

Chair of the charity, Dr Graeme Sills, told the guests that Epilepsy Research UK was “the envy of the world” in the international epilepsy community, punching far above its weight in relation to the resources at its disposal. He continued: “We should be rightly proud of Epilepsy Research UK, the work that it does, and each of your contributions to that. We thank each and every one of you for your commitment, your enthusiasm, your innovative and sometimes crazy new ways to fundraise on our behalf and your continuing support. It is what keeps us going, both financially and in a motivational sense. To all of you in the room this evening whose lives have been touched or indeed turned upside-down by epilepsy but who found the strength to fight back by supporting research, I would again like to give a heart-felt thank you on behalf of Epilepsy Research UK.”

Dr Sills encouraged the researchers in the room to take inspiration from the supporters present. All of ERUK’s 2014 grant awardees attended, and greatly enjoyed talking to different supporters about their new research projects and hearing about why supporting ERUK was so important to them.

We would particularly like to thank the Rt Hon Oliver Letwin MP, his parliamentary assistant Tom Fieldhouse, and Alex Woodward for making possible such an enjoyable evening for all involved.

New President appointed

We are delighted to report the appointment of Professor Brian Neville as the new President of Epilepsy Research UK, following the retirement of Professor Alan Richens from the role.

As a founding trustee of the charity, Prof Richens was closely involved with the development of the charity from its earliest days, later serving as Chair of the Scientific Advisory Committee and then as Chair of Trustees. The charity is greatly indebted to him for giving his time and expertise so generously over the years and for his distinguished contribution to the cause of epilepsy research.

Prof Neville is Emeritus Professor of Paediatric Neurology at University College London–Institute of Child Health (UCL–ICH), having previously held the first Prince of Wales’s Chair of Childhood Epilepsy, integrating research between the epilepsy unit at UCL–ICH, Great Ormond Street Hospital and Young Epilepsy. A notable champion for the needs of children with epilepsy, Prof Neville has been a trustee of ERUK since 2007 and it is with great pleasure we welcome him now in his new role as President.
Fundraising News

AN ADVENTURE CHALLENGE FOR RESEARCH

Andy Griffiths has just returned from climbing Kilimanjaro to raise money for Epilepsy Research UK. He tells us about his battle to reach the summit and why he’s chosen to raise raise money for research.

“Climbing Kilimanjaro had always been a dream of mine. I wanted to do a real challenge, a challenge that not many people ever get the chance to do. The whole experience was a rollercoaster, right from the start with fundraising, training, buying all the necessary equipment to reaching that summit! It has been by far one of my greatest achievements but also the hardest thing I have ever done!

Nothing prepares you for the last push for the summit. The first five days were difficult but enjoyable, trekking through rainforest, alpine desert and rocky terrain, but as that final stretch approaches you are exhausted, hungry and extremely cold; battling against temperatures of minus 22 with the wind chill, the only thing that kept me going, besides sheer adrenaline, was the thought of everyone who had supported me through sponsorship, attending events, buying raffle tickets and generally getting behind me to raise awareness for epilepsy.

I chose this charity as it is a cause incredibly close to my heart. My beautiful niece, Poppy-Scarlett has Dravet syndrome which is a rare and severe form of epilepsy. She has had to battle all her life with this and suffers almost every kind of seizure. This condition has also affected her in numerous other ways too; she has severe learning difficulties, problems with balance and is also autistic.

Despite all of this, she is still the happiest, funniest little 7 year-old girl you are likely to meet! It is down to charities such as ERUK, that without research we do the better those life saving medicines can be.”

Andy self-funded his challenge adventure, so every penny of the £2,027.00 he raised goes direct to Epilepsy Research UK. Our thanks go to Andy and all of his sponsors for their fantastic support.

This country leads the world in many aspects of epilepsy research, but we could do so much more.

Say yes to more innovative research

Each year we receive requests for funding that exceed £10 million and yet we can only fund a fraction of that. We have been able to support seven research projects this year, but perfectly good research applications were rejected simply because of a lack of resources.

Please consider if you can SayYes to making a regular monthly gift to Epilepsy Research UK, and help us fund more projects next year. More research funding now will help transform the lives of people with epilepsy in the future.

If you would like to make a regular (or single) gift, please complete the donation form enclosed or donate online at www.epilepsyresearch.org.uk/support-us/sayyes. Thank you.

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Dougie Clark and The Mongol Rally 2014

Dougie Clark and two friends are taking part in the Mongol Rally this summer. They’ve built the ‘Brain Box’ which they will be driving 12,000 miles from London to Mongolia! We wish them luck for their intrepid journey. You can read more about the trip and support them here: www.virginmoneygiving.com/dougieforepilepsyresearch

NATIONAL EPILEPSY WEEK, 18-24 MAY 2014

Thank you to all who were so active in National Epilepsy Week, helping to raise the profile of epilepsy in your local areas and through your own fundraising events.

Alex Woodward secured a much sought after photo opportunity outside 10 Downing Street through his MP, Oliver Letwin, to launch his forthcoming auction of items from Premier League football clubs.

Here in the ERUK office we invited the staff from all the other offices in our building for tea and cake, and had a lively hour getting to know our neighbours and telling them all about the work of the charity.

Over £3,000 has been raised from supporters’ fundraising activities including coffee mornings, afternoon teas, office cake sales, beauty treatments, jigsaw festival, bric-a-brac and plant sales during the week. Thank you to all who took part – it’s wonderful to have such enthusiastic support!
CHRISTMAS CARD SHOP VOLUNTEERS NEEDED

We are looking for volunteers to help in charity Christmas card shops later in the year in Altrincham, Cromford, Durham, Ealing, Kingston-upon-Thames, central London, Rugby and York. If you would like to join our team of volunteers and could spare one morning or afternoon per week/fortnight from early-October to mid-December to help, please contact Shona Scott, tel 020 747 5024, email shona@eruk.org.uk, for more information.

Thank you to all our supporters for your generous donations and inspiring fundraising activities.

Celebrating a special occasion:
Richard De Courcy (60); Pamela Dunnett (65); Gordon Hayward (70); Courtney Cooper and Brian Thorpe, Kim and Andy Jones (wedding); Mr and Mrs Brian Fox (golden wedding)

New memorial funds have been set up for:
Gavin Leonard, Amelia Mee Tong, Lara Weston

Donations have been received in memory of:

Bequests have been received from:
Dorothy Baxter, Winifred Haslam

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

SPORTING EVENTS
Thank you! The efforts of all our sporting fundraisers have been truly fantastic and we would like to say a heartfelt ‘thank you’ to each and every one of you and to your many generous sponsors for such committed support of Epilepsy Research UK.

From left to right from top: Dawn Carpenter, pilloving event; Sophie Collier, skydiving; Damien Pool, Simon Johnson, Luke Johnson, Great Manchester Run; Claire Yandall, Cardiff 10K; Mark Randall, Tough Mudder; Roseline Mbaya, BUPA London 10,000; Frankie Ashworth, cycling across the USA; Lindsay de Beer, BUPA London 10,000; Cheering team, London Marathon; Stuart Rogers, London Marathon; Thalia Liddell and friends, Tough Mudder; Chris Broughton, Kelly Brown, Neil Thommason, Great Manchester Run; Siobhan Kilee, skydiving; Sarah Broughton, Lichfield Half Marathon.

Big Fun Run series, July – October 2014
A fantastic series of 5k events – fun for all the family!
Open to all, you can run, jog or walk around and with locations all around the UK, there is bound to be one that is close by. Get 2 for 1 entry using the code ERUK241. You can sign up direct at www.bigfunrun.com and select Epilepsy Research UK as your charity to support.