An exciting year ahead

2016 will be an exciting year for us as it marks the 25th anniversary of Epilepsy Research UK, and we have some great events planned to mark the occasion.

We have been very fortunate to be chosen as the official charity of the British 10K Run in London in July, where we hope to see a sea of green vests running for us. On 12th November we will be holding a 25th Anniversary Gala Ball, so please save the date in your diary.

We are also launching our new legacy campaign and you will find a leaflet enclosed with the newsletter. We have partnered with the Free Wills Network to offer our supporters the opportunity to have their will written at no cost to themselves. A New Year’s resolution to put one’s affairs in order is always a good idea, and we hope that many of our supporters will take advantage of the scheme. Whilst providing for loved ones must be the priority, any bequest to Epilepsy Research UK would be greatly appreciated and enable us to fund future research.

In addition to this planned activity, our current work continues. Our Scientific Advisory Committee met recently and short-listed twenty-seven research projects to be considered for funding in March. The projects cover a wide range of areas including investigating the use of cannabinoids in the treatment of epilepsy, the link between cardiac function and SUDEP, and how to address memory problems in people with epilepsy. As always the projects chosen will be those that demonstrate the best science and the prospect of delivering advances in our understanding of epilepsy. Also in March we will be producing an impact report outlining the progress that has been made by our researchers over recent years.

Our work is dependent on the generosity of our supporters, and we hope your support will be as constant in the coming years as it has been over the past twenty-five. Thank you.

Leigh Slocombe, Chief Executive

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Research updates

Important new insights into seizure activity

The exact events that take place during a seizure are still not clear, and this is a barrier to the development of better epilepsy treatments.

Dr Ivan Pavlov and colleagues, at University College London, have recently made some exciting discoveries that will greatly increase our understanding. Here we report on the final results of their research project, Optogenetic control of GABAergic interneurons during epileptiform activity, which was funded by Epilepsy Research UK in 2013.

BACKGROUND

Anti-epileptic drugs successfully control seizures in about two-thirds of people with epilepsy, but because they act on mechanisms that occur throughout the brain, they often cause unwanted side effects (e.g. lethargy, weight gain, personality changes). There is an urgent need for new treatments that target pathways that are specific to epileptic activity, and that do this as early as possible in the lead-up to a seizure. However, the ‘events’ that occur just before a seizure are still not fully understood, and this is a major obstacle to progress.

The work of Dr Pavlov and colleagues, at University College London, focuses on the activity of inhibitory neurons (which have always been thought to dampen excitability in the brain) before and during a seizure. Recent findings, both by Dr Pavlov’s team and others, suggest that, in certain circumstances, networks of inhibitory neurons may actually promote seizure development. The current project aimed to explore this further.

METHODS

During the study, the team combined seizure detection methods with a technique called optogenetics, in living and experimental epilepsy models. Optogenetics allows specific groups of neurons to be activated (‘turned on’) or suppressed (‘turned off’), with great accuracy, by flashing light of a certain wavelength on them. This is called ‘photostimulation’. The group used optogenetics to target different types of inhibitory neuron and find out more about their role in seizure activity.

FINDINGS

The group discovered that identical photostimulation could have either a pro-epileptic or anti-epileptic effect, depending on the nature of epileptic activity that was occurring at that time. They also found that suppressing or activating a particular type of inhibitory neuron produced completely opposite effects (curbing or promoting epileptic activity) depending on the time interval since a seizure had begun.

In light of these findings, the researchers suggest that, as seizure activity evolves, the contribution of different types of inhibitory neuron changes, and that, therefore, the timing of an intervention, as well as its action, is critical to the effect on epileptic activity.

SIGNIFICANCE

These findings greatly increase our understanding of the events surrounding a seizure, and this will potentially lead to the development of more targeted epilepsy treatments. The hope is that these therapies will be more effective than existing ones, with fewer side effects, and that they will benefit people whose seizures are currently uncontrolled.
The role of the immune system in epilepsy

Professor Bethan Lang and colleagues, at the University of Oxford, have been investigating the role of the immune system in epilepsy and whether, for some people, a different type of therapy to conventional anti-epileptic drugs may be more appropriate. Here we bring an update on their work and findings to date.

BACKGROUND

In a previous project funded by Epilepsy Research UK, Professor Bethan Lang and colleagues showed that, among people with different types of epilepsy, many carried antibodies against certain brain proteins (these are known as autoantibodies because they attack the body’s own tissue). The group wondered if these, and other, autoantibodies might underlie certain cases of epilepsy that were previously thought to be idiopathic (of unknown cause). If so, they wondered if some of these people might benefit from a treatment called immunomodulation, which targets excessive immune responses, in addition to or even instead of standard anti-epileptic drugs (which they may have responded poorly to).

THE CURRENT STUDY

In the current project the team planned to explore these questions, in 300 adults with new-onset focal epilepsy. They proposed to take a very detailed medical history from each person, and obtain a blood sample that they would screen for a number of autoantibodies using existing diagnostic tests. They then planned to analyse each sample in the laboratory for any additional autoantibodies that weren’t detected via these tests. The group also intended to examine blood samples from people without epilepsy (controls) to confirm the significance of the autoantibodies in epilepsy. For some people with epilepsy who tested positive for autoantibodies, the researchers planned to introduce immunomodulation therapy, either instead of or in addition to anti-epileptic drugs, and monitor them for improvements in their conditions.

WORK & FINDINGS TO DATE

So far the team has recruited 224 people with new onset focal epilepsy and taken careful histories from each. Participants have also undergone a number of cognitive tests, so that the researchers have a complete medical profile. Blood samples from the 224 subjects, and over 300 people without epilepsy (controls), have been analysed, and 15% of the epilepsy group, compared to less than 1% of the controls, have tested positive for autoantibodies.

Among those with epilepsy who have tested positive, a number have already been treated with immunomodulatory drugs (either instead of or in addition to standard anti-epileptic drugs) and the effects on their symptoms have been encouraging.

The laboratory investigations have also revealed several additional autoantibodies in people with epilepsy that are not currently detected by diagnostic tests. The researchers are now investigating ways to address this.

WORK REMAINING

The recruitment period for the study is now coming to an end. In the final months the team will focus on assessing the clinical histories of the subjects alongside their blood and cognitive results, in order to determine whether or not there are characteristics that highlight people with focal epilepsy who might benefit from early immunomodulation therapy. If this is found to be the case, it will be of great help in a) reducing delays to appropriate treatment for some people and b) in preventing these people from having to trial a number of anti-epileptic drugs unnecessarily.

We are very excited to read the final report for the project in summer 2016.

International League Against Epilepsy UK Chapter Annual Scientific Meeting

The International League Against Epilepsy UK Chapter (UK ILAE) held its Annual Scientific Meeting on 23-25 September 2015, at the Institute of Education in London.

Approximately 300 scientists, clinicians and charity representatives gathered to hear the latest information on a range of topics, including epilepsy genetics, new anti-epileptic drug targets and optimising current epilepsy treatment. There were also a large number of poster presentations by researchers across the UK.

As in previous years, Epilepsy Research UK and UK ILAE held a joint basic science competition at the meeting; with a prize of £500, the Celine Newman Prize, generously supported by ICAP. Five upcoming researchers gave short talks for the project in summer 2016.

We'd like to congratulate Dr Magloire on his success, and thank all of the candidates for their efforts.

Proceedings published

The proceedings of our last international expert workshop, SUDEP: time for prevention. Evidence and clinical translation have now been published in a special supplement of the prestigious journal Epilepsia. The supplement summarises the presentations and discussions of approximately 50 SUDEP experts from around the world, reviewing both current knowledge and the steps required for protective strategies to be brought to clinical practice.

Please contact us at info@eruk.org.uk, or on 020 8747 5024, for details of how to access the supplement.

SUDEP Awareness Day

We were pleased to support SUDEP Awareness Day on 23 October 2015, an initiative launched by SUDEP Action to raise awareness about SUDEP (sudden unexpected death in epilepsy), its risk factors and to highlight the need for more research into this tragic event.

To read more about the research ERUK is funding to help overcome SUDEP go to the ‘What is epilepsy’ section on our website.
SAVE THE DATE FOR OUR
25TH ANNIVERSARY
GALA BALL!

To mark our 25th anniversary we will be hosting the 2nd Epilepsy Research UK Gala Ball. This will take place at the 5* Grange St Paul’s Hotel, London, on Saturday 12 November 2016.

We would be delighted if you were able to join our celebrations and we invite you to attend what promises to be a fantastic evening! Further details, including a booking form for tickets, will be given in the next newsletter.

Tickets are £100 each and can be booked individually or in tables of ten. The evening will begin with a champagne reception, followed by a sumptuous 3-course meal and entertainment. A raffle and auction will take place where a host of fabulous prizes will be on offer, and a silent auction will also be running throughout the evening.

To pre-book your table, please email jo@eruk.org.uk or call 020 8747 5024 and we can take reservation details. If you have any contacts for any great prizes that you think would add value to our evening, please do get in touch too!

OFFICIAL CHARITY OF THE 2016 BRITISH 10K LONDON RUN

We are delighted to have been chosen as the official charity for the British 10K London Run, which takes place on Sunday 10 July 2016.

Please consider joining Team ERUK in our 25th anniversary year, to make this the best running event that we have ever had and raise even more money for research! We have over 100 places on offer to our supporters – all we ask is that you aim to raise a minimum of £103 in sponsorship to represent the 1 in 103 people living with epilepsy in the UK today.

It’s a fantastic 10K run, which takes you through the heart of London, past world famous landmarks, and we will be there on the day cheering you along on the course and celebrating with you afterwards at our post-race reception.

To have over 100 runners in the event, all wearing Team ERUK green, would be a fantastic achievement and raise both much-needed funds and awareness for epilepsy. Please help us make a difference and transform lives through research.

To book your place, get in touch with Jo on jo@eruk.org.uk, call 020 8747 5024, or download the entry form on our website.
transforming lives through research

Purple Day & National Epilepsy Week

Once again we’re looking forward to some great fundraising activity this year on Purple Day, 26 March 2016 and in National Epilepsy Week, 15-21 May 2016.

Please think about how you might like to use these events to spread awareness about epilepsy and raise money for research. We’ll have fundraising packs full of ideas for Purple Day and National Epilepsy Week, and resources to help make a great success of your activities. To register your interest and request a fundraising pack please call the office on 020 8747 5024 or email info@eruk.org.uk.

News updates on our plans for Purple Day and National Epilepsy Week will be posted on our website and Facebook page.

It is only through more research that we will see real benefits to those living with epilepsy – your support is vital to achieving this!

Waking up to Epilepsy, 20 April 2016

Epilepsy Research UK is supporting this one-day conference at the University of Exeter Medical School, which aims to inform people from all backgrounds about a range of epilepsy topics.

Perhaps you have or know someone who has epilepsy and you’d like to know more; or maybe you are a medical professional and you would like to brush up on your knowledge. Whoever you are, this is an important opportunity not to be missed.

For more information and details of how to register, go to www.epilepsyresearch.org.uk/waking-up-to-epilepsy-20-april-2016, email UEMS_CPD@exeter.ac.uk or call 01392 722964.

Social media activity

ERUK Communications Director, Deborah Pullen, gives an update on our social media activity.

You may recall that our social media programme on Facebook and Twitter kicked off at the very end of April 2014, so in June of this year I presented a full year’s worth of data and analysis to our Board of Trustees. Against the objectives we set ourselves I am glad to say that we saw a significant improvement in our awareness scores and a concomitant increase in the number and value of donations made towards our research. As a result the Board committed to continuing with the programme, which is great news.

To move on to the next stage, the Board also approved a test to see if small scale online messaging might further generate awareness of ERUK and in time, increase our income. At the beginning of October we began our contextual and re-targeting activity so if you suddenly started to see messages from us online, then you now know why. We developed three different formats so that we could carry three different messages with a selection of images of some of our supporters. All of this is very exciting for us and together with other plans that we have for the year ahead, should help to see us grow still further in stature and help us to make even more grant awards in the coming years.

To follow our social media activity go to www.facebook.com/EpilepsyResearchUK and twitter.com/EpilepsyRUK.

Make or update your Will for free

Thanks to our membership of The National Free Wills Network we are able to offer you the opportunity to have your Will written by a local solicitor.

This is a limited offer, which will operate on a first-come, first-served basis without any obligation on those who take up the offer to include a bequest to Epilepsy Research UK. Simply call the ERUK office on 020 8747 5024 and we will arrange for the National Free Wills Network to send you the names and addresses of at least two local firms of solicitors taking part in this scheme. The solicitor will draw up your Will and you won’t have to pay the bill.

You don’t have to include a gift to Epilepsy Research UK in the Will you write, but we do hope you’ll want to, after you’ve provided for loved ones, as your gift will fund research that will benefit future generations.

“Any person who has epilepsy, I’d like to help in some small way to fund research.”

Sue Erskine

Anyone of any age, gender or ethnicity can develop epilepsy

Our scientific advisory committee will soon be making its research funding decisions for 2016. You can help us now to fund even more promising research in the future by making a regular monthly gift to Epilepsy Research UK.

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.

"Make or update your Will for free"

"My son has epilepsy. I'd like to help in some small way to fund research."

Sue Erskine

"There is no cure for epilepsy"

"1 in 103 people in the UK have epilepsy"

"translating lives through research"
FUNDRAISERS IN ACTION

A heartfelt thank you to all who fundraise for us with such incredible drive and ingenuity, many doing so in memory of a family member or friend. Whatever you choose to do for us, your efforts are absolutely vital to our research funding.

Focus on FUNDRAISERS

Alice and James Byron’s son, Arthur, was born with an underdeveloped brain, and epilepsy that couldn’t be controlled. Here Alice tells us about Arthur’s bravery in life, and their drive to fundraise for research in his memory.

“Last July, along with three of our amazing friends – Ben Huime-Cross, Lee Netherton and Moswen Brooks – James undertook our ‘Great Glen Triathlon’. The guys’ challenge was to cycle the length of the Great Glen off-road from Inverness to Fort William, then climb up to the summit of Ben Nevis, and finally kayak back through the Great Glen lochs to return to Inverness – all in less than a week. A 150-mile round trip tackled the hardest way we could think of.

This is why…

The first time we knew our son Arthur was poorly, was in a moment of silence just after he was delivered. Within an hour Arthur was diagnosed as showing signs of abnormal brain activity – seizures.

James and I were told from the outset that our time with Arthur may be short. At points Arthur suffered 60 or 70 seizures in a single day. The doctors fought to bring his epilepsy under control, but as one consultant told us the treatment of epilepsy could be more of an art form than a science. We were on the edge of medical understanding. No simple combination of drugs or diet would work for Arthur.

Ask any parent and they will tell you that you never get used to watching your child have a seizure. For nearly seven months James and I comforted Arthur while seizure after seizure overtook his body.

Arthur died on 6th July 2013. For me, there is a part of life that stopped when we buried Arthur. But the world has kept on turning. More babies have been born with underdeveloped brains. More parents have sat and watched their child fit. And more doctors have tried to make it stop.

So two years on from the week that Arthur died, James and I returned to the edge of medical understanding. But this time to show our support for those trying to figure out the ‘whys?’, ‘hows?’, and ‘what ifs?’ of epilepsy. We’re raising money for Epilepsy Research UK so that maybe one day another baby like Arthur won’t have to go through what he did. And if our fundraising is enough to stop one other parent from having to watch as their child seizures – that will be enough for us.”

James and team successfully completed their Great Glen Triathlon raising £6,643.53 in sponsorship from their amazing efforts! Our thanks go to James, Ben, Lee and Moswen, and their support team of Alice and Nim, for such inspirational support of our research.

See the Real Stories section on our website to read an extended version of Alice’s article.
Thank you to all our fantastic sporting fundraisers for your tireless efforts to fundraise for us. We’re so grateful to you and all your many generous sponsors for all you do to support our research. Here are some of Team ERUK in action!

SPORTING EVENTS

Christmas card sales and donations

Many thanks to all who supported our research this Christmas by making a seasonal donation, buying our Christmas cards, organising sales of Christmas cards and goods, and volunteering in the Cards for Good Causes and other charity Christmas card shops around the country.

Your generosity in supporting our research at Christmas-time is much appreciated.

Thank you to all our supporters for your generous donations in recent months.

Celebrating a special occasion:

Lisa Anderson, Beccy Davison, Mark Jennings, Mhairi & Tim Smith (wedding); Ian and Anne Allan (ruby wedding); Mr & Mrs D Goodwin, Edward and Wendy Grabham, Jim & Frances Harlow, Mr & Mrs B Holden (golden wedding); Charles Cushing (90).

Bequests have been received from:

Mr Martin Adams, Mr John Bamber, Mr Robert Bateman, Mrs Vivien Cairns, Mrs Olive Clear, Miss Ann Goss, Mrs Dorothy Greenhouse, Ms Karen Houghton, Mrs B Jackson, Ms Irene Lavelle, Mrs June Newton, Mrs Margaret North, Mrs Nora Ogden, Mrs Gladys Walshe, Mrs Marjorie Wood, Miss Tilde Woodcock.

Names of those in whose memory we have recently received donations are given on our website: www.epilepsyresearch.org.uk/support-us/given-in-memory

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

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CALENDAR OF EVENTS 2016

Looking to get active this year? Why not raise money for a great cause at the same time and join Team ERUK in one of our sporting events. Or, if you’re looking for a different experience—take on one of our adventure challenges while fundraising for research!

See our Calendar of Events for details of our what we have on offer, including the British 10K London Run for which we are delighted to be the Official Charity. All entry details can be found on our website and we also welcome supporters with their own places in any event to be part of Team ERUK.

For more information or to register your interest in fundraising for us at one of our events please contact Jo via email at jo@eruk.org.uk or call 020 8747 5024.

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