

## The Foundation Family

In this issue of Focus we are featuring some of the people who play an important role within the Foundation, our supporters, trustees and researchers.

The Foundation has enjoyed another very successful year and we are anticipating being able to award a record number of research grants when our Scientific Advisory Committee meets in March. This success is entirely due to the generosity of our supporters, the majority of whom have personal experience of epilepsy and the devastating effect it can have on a person's life.

This is particularly true of the Cronshaws and the Scourses, two families who have lost a child to epilepsy. They have both set up memorial funds within the Foundation and they use their fundraising activities to remember their loved one in a positive way and support those living with epilepsy in the UK today.

Here are their stories:

### The David Scourse Memorial Fund



"David was 23 when he died from epilepsy. He was a wonderful son, grandson, brother, uncle and cousin. A year before his death he was awarded a First in Physiology (Medicine) at Oxford University. He died 2 years before he would have qualified as a doctor.

The family knew that a positive response to this awful tragedy was the right way forward. We grieved and grieved; we still grieve - but we have moved on. David was himself extremely positive and altruistic. He pleaded with us

to help others in all kinds of distress and even on a student loan made a standing order to Save the Children. A few days after his death his positive words kept coming through the mist of tears. "Do something - and do it cheerfully!"

We quickly found out about the Epilepsy Research Foundation and knew it deserved every support. David was himself interested in research. David's memorial fund has been a wonderful focus for our energy and that of many of David's

friends. Marathon runs, coffee mornings, cream teas, a pantomime, a concert, a James Bond evening and "Bring and Share lunches" have been incredibly exciting, uplifting and cathartic events for us all. In truth, we have all gained inspiration by channelling our thought and energy towards helping research into this difficult condition. The greatest consolation is knowing that David would say "Well done" and that very thought releases a lot of sadness. He would have added "Keep it going, there's more to do!"

*Richard and Heather Scourse  
24 January 2006*

### The Jade Cronshaw Memorial Fund



"Because the loss of Jade was so sudden and unexpected the memorial fund in her name has helped us keep her fresh in our memory and also focused on raising awareness in our community of epilepsy.

I feel as proud of her now as I did when she was alive because people genuinely want to raise funds in her name and I can't think of anyone better than the Epilepsy Research Foundation because more research into

epilepsy can only be a good thing especially if it can help prevent the loss of a loved one.

I have been approached by lots of people from our area who suffer or know some one who has epilepsy. By highlighting Jade's memorial fund I believe people are not afraid to speak about epilepsy anymore.

We feel we are doing good by having the fund- it will never bring Jade back but at least we can feel satisfaction that we are helping others. In some ways I feel Jade is a kind of figurehead for epilepsy research."

*Damian and Rachel Cronshaw  
17 January 2006*

The Foundation would like to thank the Cronshaws and the Scourses for their involvement in this issue of Focus. Our Memorial Funds play an essential part in funding the Foundation's research. This year, they are supporting Dr Torsten Baldeweg's project 'Long term neuropsychological follow-up of children who have had neurosurgical treatment for the relief of temporal lobe epilepsy'.



### A day in the life of...

**Graeme Sills**, research scientist at the Epilepsy Unit, University of Glasgow, is a member of the Foundation's Scientific Advisory Committee. His research focuses on how anti-epileptic drugs work and why they often don't work. He organises the Scottish Epilepsy Network on behalf of the Foundation.

The public perception of university scientists may be one of wild-haired, white-coat-wearing boffins performing experiments in darkened laboratories. In reality, most of us spend our working lives behind a desk, engaged in the essential business of modern research; writing up our results for publication and putting together applications for funding.

My day begins with a cup of strong coffee and a look at any emails that have arrived since yesterday evening. After that, it's time to check up on current research projects with the people who actually get their hands dirty in the lab. Mohammed is a postgraduate student from Malaysia who is investigating how



### A day in the life of...

**Thomas Jensen**, a postgraduate research student at Royal Holloway (part of the University of London) has been a Sir Desmond Pond Fellow of the Foundation since 2004. He has epilepsy himself and will be running the London Marathon this year to raise money for the Foundation's work.

My day starts well as I had a good night's sleep with only a few seizures last night. This is important as I have a busy day ahead of me: I am running two experiments and have a meeting with my PhD supervisor Dr Ruth Empson at 3pm.

Once at work I prepare my experiments. Both centre on the role of calcium pump activity in regulating the delicate balance of excitation and inhibition in the hippocampus, a seizure-prone region of the brain. The first experiment uses electrical recordings from cultured brain cells to investigate how the loss of calcium pumps affects excitatory electrical activity. The second experiment is investigating if the amount of calcium pumps in cells is affected by electrical activity of the type that occurs during seizures.

By 10am I have prepared for my meeting and my first experiment is set up. I begin trying to get good electrical recordings from cultured brain cells. Although this can be very frustrating, by 2:30pm I have two good recordings which show that the loss of calcium pumps causes a surge in excitatory

genes influence blood concentrations of anti-epileptic drugs and Oliver is a medical student who is conducting pilot experiments on a brain-imaging project that has been approved for funding by the Foundation and which will start in summer 2006. With no major problems to report, I spend the remainder of the morning reviewing a scientific paper submitted to a scientific journal or a funding application on behalf of a grant awarding body.

The largest portion of my day is given over to some form of preparation: an ethics application, a presentation, an experimental protocol, a research report or paper, or an application for funding. Productivity in this aspect of my job can be highly variable. Even on a good day, progress is slow because I can be extremely picky. Afterwards, I'll spend an hour sifting through recent publications in the epilepsy field. To keep abreast of important discoveries, I aim to read at least one epilepsy-research paper every day. As the afternoon draws to a close and the grey matter begins to tire, I'll deal with any administrative paperwork that doesn't require much intellectual effort. One final sift through the emails and it's time for home.....

It may not be the most glamorous job in the world but it can be extremely rewarding. Training the next generation of scientists is exciting, and because I work closely with a team of doctors who treat people with epilepsy, the impact and importance of my research is immediately clear.

electrical activity. So at 3pm with my latest results I go into my meeting confidently. Dr Empson and I talk about how the results fit in with previous experiments and the work in my PhD thesis. Although the meetings take precious time from a day's work, they are invaluable as they focus my mind on the work ahead.

After the meeting I start my second experiment. It has taken weeks to prepare so I am apprehensive about its outcome. The results are mixed: the amount of calcium pumps are increased in some samples where seizure-like electrical activity occurred, but not in all the samples. This result is disheartening but I know that science never works perfectly first time around.

It is the end of a day which has had both ups and downs, and I make the long walk home in the cold to get back in time for my marathon training. Putting my work into perspective, I can see that its outcome is many years away; but as one of many epileptics who have run out of new medicines to try and whose seizures are still uncontrolled, I see the true benefit of this work to both my and many other people's lives. Who knows, what I and other researchers working with the Foundation's support are doing now may even allow me to drive home in the future.

If you would like to sponsor Tom Jensen's London Marathon run on 23 April you can do so online at [www.justgiving.com/TomJensen](http://www.justgiving.com/TomJensen) or by sending a cheque made payable to Epilepsy Research Foundation to: Epilepsy Research Foundation, Dept FLM/TJ, Freepost (PAM 6963), London W4 1BR



### A day in the life of...

**Richard Appleton** is a Consultant Paediatric Neurologist at the Royal Liverpool Children's Hospital (Alder Hey). He is also a trustee of the Foundation and the chairman of our Scientific Advisory Committee.

No two days in my week and no two weeks are the same.

I'm usually at my desk in Alder Hey by 7.45 am, checking my email. On Tuesday mornings I teach the junior members of our neurology team. Today the subject is epilepsy that develops in the first year of life. Interpreting 15-20 children's EEGs (together with EEG specialists) from infants a few days old to teenagers aged 16 occupies the next two or three hours.

Twelve noon sees me scrutinising today's post: usually at least 20 letters about patients, test results, plus invitations to speak at conferences, review scientific papers or prepare medico-legal reports. I quickly touch base with the junior doctors in the neurology team and the nurse specialists in epilepsy, about

inpatients or new referrals. During lunch I answer emails and calls and (if possible) read medical journals to keep up-to-date with the latest research. I focus on the investigation, genetic basis and treatment of patients with epilepsy and the rehabilitation of children following brain injuries.

At 1.30 pm I hold a clinic for new patients, all referred for a second or even third opinion. Today's list includes Jack, 20 months old, with a very nasty epilepsy syndrome called migrating partial epilepsy in infancy; Michael, who's 15, and has frequent seizures that started five years after he had a brain tumour removed; and Helen (5 years old) who has myoclonic-astatic epilepsy. I recently started her on a second anti-epileptic drug to try and improve her seizure control.

At the end of the day I review the children on the wards who are particularly unwell, including a rapid round on the intensive care unit. Here there's a teenager with a severe head injury after he was knocked down by a hit-and-run driver; and a 6-year-old transferred from a local hospital in convulsive status epilepticus.

Home looms (at last) at 7.30 pm, in the company of a Beethoven CD. The evening sees some NHS, academic or Royal College of Paediatrics and Child Health-related work, facilitated by an understanding family and the odd glass of red wine. To sleep, and perchance to dream...

### Christmas

Thank you to all who bought our Christmas cards by mail order, via the website and through the Cards for Good Causes and Card Aid shops increasing the quantity sold for yet another year. Thanks also to those supporters who responded to our Christmas Appeal or made a donation with their Christmas card purchases raising over £5,500 for epilepsy research.

### Payroll giving

The payroll giving scheme provides a flexible, tax-efficient method for an employee to make regular donations to the charity of their choice. The government is currently offering a grant to employers of less than 500 staff to set up payroll giving schemes and will match pound for pound the first £10 of employees' monthly donations for the first six months. This incentive ceases at the end of December 2006 so do consider soon the possibility of organising such a scheme in your workplace. Further information is available from the Foundation or from Payroll Giving, telephone 0845 602 6786 or visit [www.payrollgivinggrants.org.uk](http://www.payrollgivinggrants.org.uk).

### Sponsored events

Individuals entering sponsored runs and other events play a major part in increasing the funds we have available for epilepsy research.

In November 2005 Caroline Trask raised over £1000 and Sohail Janjuha over £1500 by running in the New York Marathon. Our thanks to both runners for their enterprise and commitment.

The Foundation was represented in the Great Manchester Run

2005 by Abigail Bond, Daniel Bradley, Eleanor Cribb, Joanna Driscoll, Diane Hollingworth and Christopher Johnson, and in the Great South Run 2005 by Hannah Dodkin, Katie Fung, Nicola and Victoria Larder, Chris Morbey and Matthew Newnes. Thanks to all these runners for their efforts in raising over £2,000 for the Foundation.

For those who enjoy active fundraising we are able to offer this year a wide range of sponsored events ranging from a 1-mile walk to the marathon. All events can be entered individually, but why not consider taking part with a group of family, friends or colleagues.

The Great Scottish Walk on 18 June is an ideal family event, open to all ages, with three walks around Edinburgh over distances of 1, 6 and 12 miles.

If you want to take on a more strenuous challenge for the Foundation we have just a few places remaining in the Edinburgh Marathon on 11 June, the UK's second largest marathon. It follows a spectacular route around the city with magnificent views and is a much less crowded course than London's. Edinburgh also offers a popular Marathon Team Relay event for a team of five with stages of between 4 and 7 miles long.

For the first time we will be entering teams in the Great Edinburgh Run (10K) on 7 May and the Great North Run (half marathon) on 1 October 2006. Other popular events in which we still have guaranteed places available are the Great Manchester Run (10K) on 21 May, the British 10K London Run on 2 July and the Great South Run (10 miles) on 22 October.

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The Foundation has been made the official charity of the Fuller's Thames Towpath 10 on 9 April, a 10-mile race along the Thames towpath starting from Chiswick in west London. The Thames Towpath 10 is organised by West 4 Harriers and entry can be made at [www.west4harriers.org](http://www.west4harriers.org).

Let us know at the office if you would like further information about taking part in any of these events.

### Fundraising events

The Cronshaw family and their friends have had a busy few months fundraising in memory of Jade. A quiz night, beer festival, a raffle, a scheme of donating to the Fund rather than sending Christmas cards ran by local businesses and a celebration on the anniversary of Jade's birthday contributed nearly £3000 to the Jade Cronshaw Memorial Fund. Well done for continuing to involve the community in your fundraising efforts.



Denise Brain from the Forestry Commission organised a Cycle Ride through the Forest of Dean in September 2005. The event proved to be a great success, raising £2176.50 for epilepsy research.

The Whiting family raised £1,500 in memory of Brett Whiting from a Sunday barbeque in May 2005, making a fantastic contribution to the Foundation in Brett's name.

Staff from Blackpool NHS trust organised 'A Walk for Jane' and raised nearly £700. Stan Quinn coordinated a charity football

match which contributed over £1,200 to the Jane Quinn Memorial Fund.

The Kasia Gonzalez Memorial Fund received a further £150 from a colouring competition.

An impromptu raffle at the Aylesbury Sorting Office produced £50 for the David Foote Memorial Fund.

Sylvia Lambert's coffee morning contributed £100 to the Epilepsy Research Foundation in memory of Edwin Wood.

Mr and Mrs Hunter raised £550 in memory of their son Charlie. The donations were made to the Foundation in place of gifts for their Silver wedding anniversary.

Jack Miller also asked for donations in place of gifts for his 70th birthday in memory of his son Alex. The Foundation is very grateful to Mr Miller's friends who donated a total of £270.



The David Scourse Memorial fund benefited from a James Bond Evening in January. Kate Bishop, Jackie Meldon and Terina Wallis raised £1,880.60 from their efforts and, as the photo shows, the event was a great success.

### In memoriam donations, memorial funds & legacies

Since the last newsletter we have received donations in memory of the following people:

Caris Aparicio, Betty Birkenhead, Peter Black, Mark Bradley, Glenda Buffin, Albert Bryant, Hilda Crowther, Mark Dawson, Elizabeth Drummond, David Eaton, Gillian Edkins, Jeremy Evernden, Hilda Fisher, James Flaherty, Christopher Gibbons, Sandra Hall, Jonathan Harris, Charlie Hunter, Branko Jevtic, John Lindley, Harold Morris, Barry Palmer, Esther Protheroe, Denise Purkiss, William Saul, Robert Sindall, Mandy Sowerby, Stefan-Paul Stewart, Jennifer Sykes, Wilfred Walls and Hector Wilkins.

New memorial funds have been set up in memory of Samantha Penicott and Jamie Chivers. In addition to the memorial funds supported through the fundraising events listed above, the following funds have also received donations: Jonathan Bevan, Joan Brailsford, Alexander Buckman-Drage, Colin Chilton, Edna Collings, Mark Collins, Edward Daw, Nick Drake, Ian Ferguson, Jonathan Graham, Jacqueline Jones, Stephen Lang, Jill Sloan and Steven Shaw.

The Jacqueline Jones Memorial Fund received a legacy from Professor Peter Lewis Clarke

Legacies are an important part of the Foundation's income and we are grateful to supporters who chose to support our work through gifts in their will. With each legacy we receive, more research is funded, helping to change the future for people with epilepsy.

Bequests have been received recently from George Drewry, David Spencer Wells, Dorothy Edith Hopes and Alan Inglis. We hope our research will be a fitting tribute to their memory.

#### Donation and Information Request Form

I would like to support the Foundation's work and enclose a cheque/ postal order/CAF voucher payable to Epilepsy Research Foundation for:

£15  £25  £50  £100  or I prefer to give £ \_\_\_\_\_

or I wish to donate by Switch/MasterCard/Visa/Amex/CAF Card (delete as appropriate)

Card Number \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Expiry date \_\_\_\_/\_\_\_\_/\_\_\_\_ Issue No \_\_\_\_\_ (Switch only)

Cardholder's signature .....

Please send me information on:

- making a regular donation to the Foundation
- Payroll Giving
- entry for Great Scottish Walk/Edinburgh Marathon/Great Edinburgh Run/Great North Run/Great Manchester Run/British 10K London Run/Great South Run/Thames Towpath 10 (delete as appropriate)
- fundraisingdinner.com

Name .....

Address .....

Postcode .....

Tel ..... Email .....

#### Gift Aid Declaration

I want to Gift Aid all my donations to the Epilepsy Research Foundation until further notice. I understand that to be eligible I need to be paying an amount of income and/or capital gains tax equal to, or more than, the amount the Epilepsy Research Foundation reclaims on my donations (currently 28p per £1)

Signed ..... Date .....

Please complete this form and return it to: **Epilepsy Research Foundation, FREEPOST (6963), London W4 1BR.** Thank you.

We like to keep you informed about the work you are helping to make possible, but if you would rather not be written to, please tick here  February 2006

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