

2011

BRTreview

Annual Review of Brain Research Trust, registered charity (no 1137560)



Prof Lemieux has developed a new scanning method for epilepsy

New technique tested to increase success of epilepsy surgery

Epilepsy is one of the UK's most common neurological conditions with over 400,000 people affected. Medication is often prescribed, but some people find that their symptoms cannot be adequately controlled through drug treatments and therefore require surgery to reduce or stop their seizures. Brain Research Trust funding is enabling a new non-invasive technique to be tested for determining the suitability of patients for the procedure.

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A record year for funding world-class brain research

Welcome to our review of 2009/10.

Despite a difficult economic environment, we invested the record sum of £2.3 million in research in 2009/10 (£1.8 million in 2008/09) and we owe this all to you, our supporters. Whether you donate through your trust or community group, with a regular or one-off cash gift, sponsored events or fundraising activities, we are very grateful to you.

Thanks to you we are able to give hope to the more than 10 million people in the UK who are affected by a neurological condition including Alzheimer's and other dementias, Parkinson's, Multiple Sclerosis, Motor Neurone Disease, Stroke, Brain Tumour and Epilepsy.

Since our founding in 1971, our BRT-funded scientists have delivered many breakthroughs. We are committed to finding better ways to diagnose, treat and prevent brain diseases and even cure them. Working at the Institute of Neurology in London, a renowned world-class centre of neurological research excellence, BRT-funded scientists share their learning, sometimes applying discoveries from one condition to another for the benefit of many more people.

I hope you will enjoy reading about some of the research projects we have funded and some of our supporters' fundraising efforts. Once again thank you for your

generous contribution to our research. We are very grateful to each of you and hope that we may count on your continued support.




Neil Payne
Chairman, Brain Research Trust

Find out more about our research projects at www.brt.org.uk/conditions

Huntington's Disease
Migraine

Tay-Sachs Disease
Autism

Epilepsy
Multiple Sclerosis

Stroke
Brain Tumours

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Tests are carried out prior to surgery to help pinpoint the part of the brain from which seizures originate. In some cases, the location cannot be found using traditional imaging techniques (MRI) and may require electrodes to be inserted into the brain, which is invasive, expensive and carries health risks. Instead, Professor Louis Lemieux and his team have developed a new scanning

technique called EEG-correlated fMRI, which in laboratory studies has provided a new means of finding the origin of seizures.

Thanks to a Brain Research Trust grant, Professor Lemieux's team have purchased equipment to implement this technique in a clinical setting and record the results of the research. During 2009/10 and using these new tools,

Professor Lemieux started the patient study. The team hope that this new method will reduce the need for invasive tests in future and help increase the likelihood of successful surgery for all patients.

We are most grateful for the support of a number of trusts, including The James Tudor Foundation, which have enabled Brain Research Trust to fund this equipment and research.

Deep Brain Stimulation changes lives



Robert Knight, aged 43 from Hertfordshire, undergoes Deep Brain Stimulation for Myoclonus Dystonia in March 2011

Deep Brain Stimulation (DBS) enables the safe placement of electrodes into the brain with millimetre precision. The technique has been used for decades to treat patients with chronic pain and tremor – and more recently Parkinson's Disease – as it can control shaking, slowness and stiffness. This helps maintain the quality of life of people affected for years beyond what conventional medication could achieve. DBS is now routinely used for people with Parkinson's, Dystonia and other forms of tremor and is being evaluated for treating cluster headaches, Tourette Syndrome, Epilepsy, Obsessive Compulsive Disorder, Major Depression and even dementia. Brain Research Trust funded Dr Thomas Foltynie says **“Being responsible for DBS patients is perhaps the most rewarding job in neurology today. Major disability can be relieved at the flick of a switch. This is a life-changing treatment”**. With colleagues, Dr Foltynie aims to further improve the procedure and expand the service to a wider range of patients, whilst broadening our understanding of brain function and neurological illnesses with each individual undergoing the operation.

BBC Radio 4 Appeal for research into Motor Neurone Disease



On behalf of Brain Research Trust, broadcaster Sheena MacDonald (pictured), herself a survivor of a major brain injury, presented an appeal for donations on BBC Radio 4 in June 2010. The appeal focused on our research into Motor Neurone Disease (MND) and raised more than £11,000.

Motor neurons are highly specialised nerve cells that send signals from brain to spinal cord then to muscles. MND causes these cells to dysfunction and die, affecting voluntary movement – walking, talking, swallowing and even breathing – but not the person's intellectual ability. So inside they are the person they always were but physically they go on deteriorating. No effective treatments exist.

During 2009/10, Professors Elizabeth Fisher, Linda Greensmith and Martin Koltzenburg investigated Amyotrophic Lateral Sclerosis (ALS), a form of MND. ALS is the third most common form of neuro-degeneration after Alzheimer's and Parkinson's diseases, but is very difficult to diagnose.

Between 10-20% of people affected by ALS have 'familial ALS' (FALS) as it runs in the family. We know that the SOD1 and TDP43 genes can cause FALS when mutated. They are particularly interesting because clumps of these proteins can also be found in neurons of individuals with many other forms of neuro-degeneration like Alzheimer's and Fronto-Temporal Dementia. Further work is necessary to understand how these mutations lead to neuro-degeneration.

Find out more about our research projects at www.brt.org.uk/conditions

Motor Neurone Disease

Huntington's Disease

Ménière's Disease

Brain Tumours

Niemann-Pick Disease

Dystonia

Tourette Syndrome

International collaboration brings us closer to understanding PSP

Several neurological disorders including Progressive Supranuclear Palsy (PSP) are associated with defects in the tau protein found in the brain. PSP is clinically similar to Parkinson's disease, but is much more difficult to treat. PSP's brain pathology is different too, and consists of collections of tau (called tangles) in nerve cells which are responsible for killing nerve cells.

When Brain Research Trust received a grant for £150,000 from The Peacock Trust, it was allocated to two PSP projects at the Institute of Neurology: Professor John Hardy (pictured) and Dr Rohan de Silva each led a team.

Dr de Silva's research focuses on two very similar forms of the tau protein in the cerebrospinal fluid (CSF) of patients. CSF circulates within the brain and the spinal cord. Measuring the changes in the tau protein in the CSF can help with the diagnosis of neurological conditions. Dr de Silva's team succeeded in collecting the largest possible numbers of CSF samples from patients, not only suffering from PSP but also from Alzheimer's and Parkinson's disease, from centres all over Europe.



Professor Hardy is an internationally-renowned geneticist

Using these samples, they developed a highly sensitive method to trace amounts of tau in the CSF. With further studies Dr de Silva and his team hope to find a diagnostic marker for these disorders.

Focusing on the genetics of PSP, Professor Hardy and his team – in collaboration with colleagues from all over the world, especially Germany and the US – have now found many other risk genes for the disease. These risk genes seem to be related to the creation of proteins which interact with the tau protein. This research breakthrough means that scientists have a much better picture of what starts to go wrong in the nerve cells that cause the disease.

Queen Square Library reopens to benefit researchers across the globe

First established in 1935, the Queen Square Medical Library reopened in June 2010 at 23 Queen Square, fully refurbished after a £1 million redevelopment. Brain Research Trust jointly funded this project with fellow Queen Square charity The National Brain Appeal.

The new library has been completely renovated and updated with 21st century technology including dual computer access to both the Institute of Neurology and the National Hospital for Neurology and Neurosurgery networks. Also a new Queen Square online 'portal' provides access to the library's digitised archives, case notes and other rare collections to international researchers and clinical communities around the world.



The refurbished library mixes traditional and digitised resources

Find out more about our research projects at www.brt.org.uk/conditions

Multiple Systems Atrophy

Motor Neurone Disease

Aphasia

Multiple Sclerosis

Creutzfeldt-Jakob Disease

Alzheimer's Disease

Ataxia

Your donations fund vital brain research

Thanks to the support of thousands of individuals, trusts and community groups, Brain Research Trust was able to fund a record £2.3 million investment in brain research in 2009/10. This will help millions of people affected by brain and neurological conditions. Here is a selection of inspiring stories from fundraisers.

Fundraiser reaches highest peak

Janet Dealey put her physical and mental strength to the test when she climbed Mount Kilimanjaro to raise money for Brain Research Trust

“I first thought of supporting Brain Research Trust because Annie, a dear friend, had suffered from CJD. Then in May 2010, my wonderful father died from a severe stroke. Both Annie and my Dad are my inspiration.”

Janet went to Tanzania last September. “The trek started in a gentle way. We were walking five to eight hours a day, gradually ascending. Each time we reached the camp sites, the tents were up and the dinner was on. Easy! But, oh boy was I in for a shock later!

“Daytime temperatures were reasonable but nights very cold. Because of the altitude the last night we had to leave our tents open. What a choice: suffocate or die of hypothermia? I ended up wearing six layers, but I was still cold!

“The final ascent will be done at night to reach the summit at sunrise,” they said. But I had a different explanation: if you were to see in daylight what you were about to climb, you would go back to your tent!



Janet Dealey, 48, from Tring, Hertfordshire, admires the view at the top of Mount Kilimanjaro and reflects on her fundraising achievement in September 2010

“Midnight 18 September, we set off and six hours later I was at the top. What a wonderful view! I had raised £1,911 – more than my target for Brain Research Trust which also gave me a much needed warm glow.”

If you are considering embarking on a personal challenge whilst supporting Brain Research Trust, call Heather on **020 7404 9982** or email **events@brt.org.uk**

We have guaranteed places for events in locations from Edinburgh to London. Runs range from 5K to marathons and triathlons can be entered as a team.

Thank you to trust and foundation partners

Income from trusts and foundations reached £383,000 in 2009/10 (38% of total voluntary income). Trusts also felt the effects of the economic turmoil and we are all the more grateful to them for continuing to invest in our research, in particular:

- The H.B. Allen Charitable Trust
- The Honourable J J Astor's Charitable Trust
- The PF Charitable Trust
- Alfred George Ker Trust
- Rene Horton & Joan Parkin Charitable Trust
- Rosetrees Trust
- The Constance Travis Trust
- The J and S Saper Charity Trust

Find out more about our research projects at www.brt.org.uk/conditions

Ataxia

Shy-Drager Syndrome

Progressive Supranuclear Palsy

Migraine

Creutzfeldt-Jakob Disease

Multiple Sclerosis Myasthenia Gravis

Remembering loved ones with online tributes

A tribute fund is a way for friends and family to remember and celebrate the life of someone they love. The MuchLoved website enables them to come together online and at the same time help Brain Research Trust continue its vital research work.

One of our supporters, Audrey Oldham from Lancaster, tells us how creating such a tribute for her dear husband Glen has helped her cope with his untimely death at the age of 44 after a Brain Stem Haemorrhage in November 2010.

“When Glen died so suddenly and at such a young age, I knew that I needed to donate to brain research in his name, to try and prevent this from happening to others. The undertaker at Glen’s funeral told me about Brain Research Trust and your wonderful work. I later went onto your website and came across MuchLoved. At first I wasn’t sure whether I wanted to do it because my memories of Glen were so personal. But upon reading the books of condolences, I realised how these little stories and memories from others helped me a little – and could help them with their grief too. I see Glen’s MuchLoved page as an extension of those books. Although the extended family stretches throughout the country we can all share our thoughts online.”



Audrey Oldham shares memories of her dear husband Glen

Audrey has put several pictures and a poem onto Glen’s page. “Glen gave me a book of poems by WH Auden and we both loved them. At his funeral a dear friend read out *Funeral Blues* but no one could really take in the words. It’s wonderful that people can now read it and think of him. I hope that more people will visit Glen’s tribute page and post their thoughts now and at anniversaries or whenever they like – and also make donations in his name to support the work of Brain Research Trust.”

To send Audrey a message or contribute to Glen’s tribute, visit glen.oldham.muchloved.com

Golf club hosts tee-r triumphant fundraising

Our research benefits people affected by neurological conditions every day – individuals of all ages, including Daniela Ciampa who was the inspiration behind her father Tony’s fundraising.

“Our family experienced the ultimate fear when our eldest daughter Daniela suffered a Brain Haemorrhage aged 27 in July 2009.

“Daniela had an operation to remove abnormal blood vessels. We put our trust into the medical team and hoped for a miracle. Thankfully Daniela eventually made an amazing recovery.



Daniela Ciampa (left) pictured with her father Tony and sister Emilia

“It was during this period that we realised that other families may not be as lucky. Our thoughts turned to why these conditions occur and how we could help researchers. Choosing Brain Research Trust as a charity to support was an easy decision. We hope that cures can be found.”

During 2010 Tony was Club Captain of Bedfordshire Golf Club. He held various fundraising activities, including a very successful auction night and numerous raffles.

“I nominated the sixth hole (par 3) as Captain’s hole: each golfer who missed the green with their tee shot was asked to donate their small change. This particular activity really captured the imagination of everyone.

“I would like to thank all members of the Club who donated or helped organise the events. The £1,600 we raised will help research which will benefit more people like Daniela.”

Find out more about our research projects at www.brt.org.uk/conditions

Epilepsy

Huntington’s Disease

Guillain-Barré Syndrome

Tay-Sachs Disease

Brain Tumours

Stroke

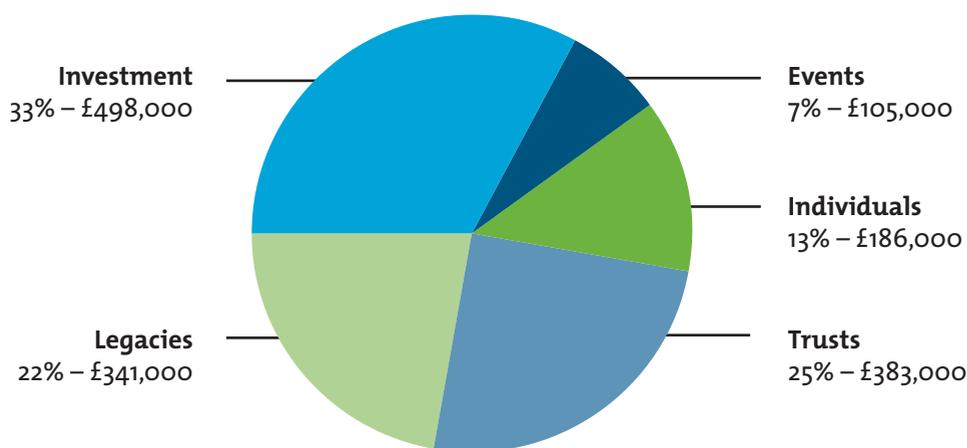
Financial review

During the period under review the Trustees decided that the charity should change its status from one of an unincorporated charity to a charitable company limited by guarantee. The charity's new charity number is 1137560 and its company number is 07345516. Our principal activities and objectives – funding research into neurological diseases – remain unchanged.

We have also taken the opportunity to simplify our name to Brain Research Trust and move our financial year end to 30 September. This period's accounts are therefore for the fourteen months from 1 August 2009 to 30 September 2010.

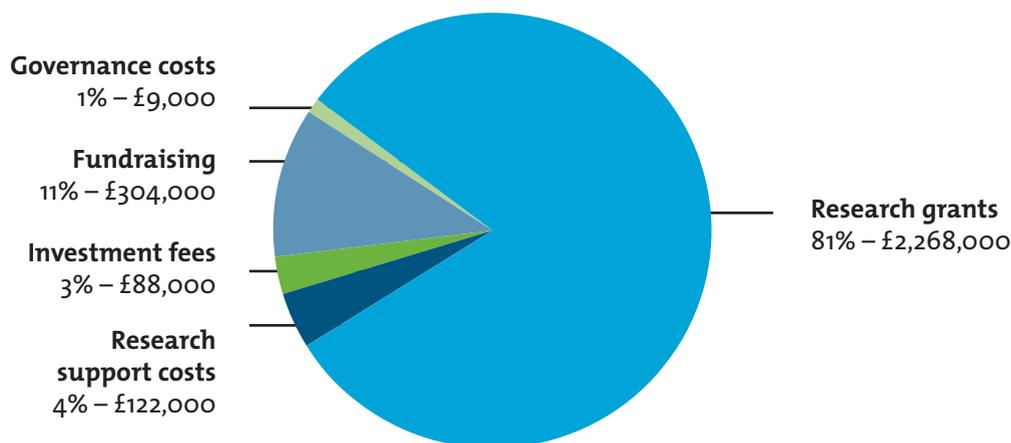
Where our money came from

In the period ended 30 September 2010, **our total income was £1,513,000**. £1,015,000 (67%) of that was voluntary income from supporters. We are grateful for your donations which have enabled us to continue our research into neurological conditions.



How we spent our money

In the period **we spent £2,791,000**, of which £2,390,000 was committed to research grants and research support. This represents 85p of every £1 spent, one of the best return-on-investment ratios in the sector.



Find out more about our research projects at www.brt.org.uk/conditions

The financial information in this Annual Review has been extracted from the Annual Report and Financial Statements for the period ended 30 September 2010 which received an unqualified audit report from our auditors haysmacintyre. These were approved by the Trustees on 9 December 2010.

The full Annual Report and Financial Statements can be obtained upon request. It is also available on our website at www.brt.org.uk/accounts

Communicating with you better

Brain Research Trust has a new staff team with ambitious plans for the future (see brt.org.uk/who-we-are) and we are keen to get closer to you. Many of you spontaneously tell us your stories and they are very touching and inspiring: they constantly remind us of why we do our jobs!

We are increasing our activities during 2011. We will launch a raffle and will be telephoning a selection of supporters to find out more about what motivates you, and tell you about our vital work. In the meantime, feel free to contact us. We look forward to hearing from you.

Please include your telephone number and email address whenever possible, as it may save us time and money when communicating with you.

Brain Research Trust
15 Southampton Place
London WC1A 2AJ
020 7404 9982
info@brt.org.uk
www.brt.org.uk

Dystonia

Multiple Systems Atrophy

Guillain-Barré Syndrome

Niemann-Pick Disease

Alzheimer's Disease

Stroke

Aphasia

Epilepsy

Projects funded

Thanks to your generosity, Brain Research Trust is able to fund the very best research projects. All applications are evaluated by our Scientific Advisory Panel and only the top ranked proposals receive funding. In 2009/10 we awarded the following grants:

Description	Disease	£
Research Grants (Main Fund Unrestricted)		
MRC Capacity Building Studentship	Alzheimer's	5,533
Peripheral markers of neuronal excitability in CNS channelopathies	Epilepsy, Ataxia	12,066
The pathogenicity of skeletal muscle channelopathies	Neuro-muscular diseases	6,674
Investigating the role of Tau in neurodegeneration by the development of a Tau Tubulin Kinase 2 Drosophila model	Ataxia, Dementia	26,372
Axonal protection by sodium channel blockade in experimental allergic neuritis and Guillain Barré syndrome	Guillain-Barré	36,074
Mitochondrial oxidative damage in Parkinson's disease	Parkinson's disease	55,459
Investigating the pathogenesis of DYT1 dystonia through study of torsin A and its interacting protein partners	Dystonia	56,431
Investigation of PARL as direct PINK1 interactor and substrate: implications for Parkinson's Disease	Parkinson's disease	32,513
Decreased chaperone mediated autophagy in Parkinson's Disease: analysis of underlying mechanisms	Parkinson's disease	59,191
Regulation of vesicular exocytosis by calcium channels in individual central synapses	Epilepsy	38,425
Influence of differential allelic expression on phenotypic severity in skeletal muscle channelopathies	Molecular neuroscience	20,493
Assessment of EEG-correlated fMRI localization of the epileptic focus in a clinical setting	Epilepsy	40,550
Research sub-total		389,781
PhD Studentships (Main Fund Unrestricted)		
Understanding cognitive dysfunction and localizing the epileptogenic zone	Epilepsy, memory disorders	423
Misregulation of alternative splicing in neurological disorders: Predictions for treatments	ALS, Parkinson's	2,744
Mutations in P/Q-type calcium channels and molecular mechanism of migraine	Migraine, ataxia, epilepsy	31,353
Counterfactual thinking and behavioural regulation	Prefrontal dementias, Parkinson's, depression	32,668
Intracellular trafficking of the abnormal prion protein (PrP ^{Sc}) and the subcellular compartments where PrP ^{Sc} mediated neurotoxicity occurs	Prion disease, neuro-degenerative disease	30,970
Identifying genetic pathways determining brain tumour phenotypes	Brain Tumours	23,771
Neuronal signaling studied with light-activated Ion Channels	Epilepsy	31,924
Does action observation facilitate corticospinal excitability after stroke?	Ataxia, migraine, epilepsy	26,460
Synaptic consequences of disease-associated calcium channel mutations	Ataxia, migraine, epilepsy	11,739
Investigating axonal transport in a panel of mice that model Down Syndrome	Down syndrome, neurodegenerative disease, motor neurone disease	28,594
Understanding the Inattentive Brain	Stroke/Parkinson's disease	23,581
PhD sub-total		244,227
Charitable Trusts + Main Fund Restricted		
Dr Nicola Potter	Brain Tumours	6,973
Senior Research Fellow in Molecular Neuroscience	Alzheimer's	60,302
Brain Tumour Fellowship	Brain Tumours	67,141
Electrical Engineer for Sobell Department of Motor Neuroscience & Movement Disorder	Neurophysiology	50,423
How is brain plasticity and connectivity altered by timing treatment initiation in Parkinson's disease?	Parkinson's disease	24,948
The long-term prognosis of epilepsy (NGPSE)	Epilepsy	27,425
Finding risk genes for PSP	PSP	25,000
A diagnostic ELISA for assessing tau isoforms in cerebrospinal fluid and pathology in PSP and related tauopathies	Molecular neuroscience	25,000
Trusts sub-total		287,212

Find out more about our research projects at www.brt.org.uk/conditions

Migraine Autism Ménière's Disease Shy-Drager Syndrome
 Creutzfeldt-Jakob Disease Alzheimer's Disease Progressive Supranuclear Palsy

Description	Disease	£
Other research support to the Institute (Endowment & Restricted Funds)		
Miriam Marks Department of Neurochemistry: for research into the blood-brain barrier, cell signaling and oxidative stress	Neurochemistry	69,978
Sobell Department of Motor Neuroscience & Movement Disorder: for research into the relationship between movement and the brain; recovery and reorganisation after spinal cord injury; Does spinal cord regeneration actually lead to recovery?	Neurophysiology	145,796
Graham Watts Laboratory: for research into the mechanisms underlying motorneurone disease	Motor Neurone Disease	125,027
A transcriptomic analysis of the role of axonal transport defects in a model of Kennedy's disease	Kennedy's disease	5,134
Leopold Muller Functional Imaging Laboratory	Cognitive neurology	452,333
University Department of Neurosurgery: Dr Tracy Warr	Brain Tumours	4,195
Unit of Functional Neurosurgery - Deep Brain Stimulation Operations	Parkinson's disease	122,631
Pilot project to investigate new physiological models of amyotrophic lateral sclerosis	Amyotrophic lateral sclerosis	4,102
High field imaging of a human glioma xenograft model	Brain Tumours	22,152
Functional imaging and response to deep brain in Parkinson's Disease	Parkinson's disease	10,833
Other research sub-total		962,181
Other projects		
Queen Square medical library improvement		380,000
Donation to unit of functional neurosurgery		2,000
Donation to "Interacting with Brain Oscillations" workshop		2,500
Other projects sub-total		384,500
Grand total		£2,267,901

Leaving a gift at your will

Brain Research Trust receives no Government funding and relies entirely on the generosity of its supporters to fund its vital research work. In the last year nearly a quarter of our charity's income (that's an amazing £341,000) came from gifts left to us in wills.

When it comes to your will, we understand that your family and friends come first in your thoughts. But you may also like to consider leaving a gift to Brain Research Trust so that we may continue delivering research breakthroughs long into the future.

Research takes time and money. Current treatments are the result of research often started decades ago thanks to the generosity of supporters and the foresight of neuroscientists. A gift in your will can make a tangible difference to future generations of people diagnosed with a neurological condition, potentially including your loved ones and their families. You can leave stocks and shares, property or cash in your will. A gift to Brain Research Trust will make a lasting difference by funding world-class research into better diagnoses and treatments for more than 250 neurological conditions – as well as cures and ways to prevent them in the first place. Including us in your will could also reduce inheritance tax on your estate.

For further information about leaving a legacy to Brain Research Trust, please contact Heather on **020 7404 9982** or email **info@brt.org.uk**

Averil Jenkyn's story

Averil Jenkyn from Highcliffe, Dorset, was devastated when she lost her son Ian aged 33 to a Brain Tumour and has been supporting Brain Research Trust through regular donations ever since.



Averil Jenkyn has included Brain Research Trust in her will

"When you hear or read statistics about cancer they don't seem to mention Brain Cancer. There are lots of charities for other cancers but we couldn't find anything for Brain Tumours. We came across Brain Research Trust after reading an article in the newspaper."

Averil then realised that Brain Research Trust also funds research into Multiple Sclerosis, which her husband Brian was diagnosed with in 1977. When the time came to rewrite her will, Averil decided to leave Brain Research Trust a gift.

"When we moved from Kent we rewrote our wills. I decided to leave Brain Research Trust a legacy because our lives have been touched by Brain Tumour and MS, and we want to do all we can to help."

Find out more about our research projects at www.brt.org.uk/conditions

Dystonia **Tourette Syndrome**
Ataxia **Motor Neurone Disease**

Myasthenia Gravis **Migraine**
Progressive Supranuclear Palsy