

Inspiring progress, together



Brain Research UK
Annual review 2016/17



Brain Research UK

Inspiring progress, together

The brain is the most complex organ in our body. It weighs just 3lb, yet it controls our emotions, senses and actions. Every single one of them. It is how we process the world around us. So when it breaks down, we break down.

It doesn't have to be this way.

There are hundreds of neurological conditions. We fund research to discover the causes, develop new treatments and improve the lives of all those affected.

We inspire scientists and families to come together, side by side, stride by stride.

Help loved ones live better, longer.

Let's unite to accelerate the progress of brain research. Today.

Image: computer enhanced electromagnetic image courtesy of M. Chamberland and M. Descoteaux from the Sherbrooke Connectivity Imaging Lab (SCIL) (<http://scil.dinf.usherbrooke.ca>).



Welcome to our annual review

Every minute, someone in the UK is diagnosed with a neurological condition. Brain Research UK funds world-class research to discover the causes, develop new treatments and help all those whose lives are affected by neurological conditions.

It is only thanks to the generosity of our supporters that this vital neurological research can be funded.

In 2016/17, we awarded £1.2 million for research projects addressing areas of unmet need and demonstrating a clear pathway to patient benefit within our three priority research areas: neuro-oncology, acquired brain damage, and headache and facial pain.

This research is being undertaken at centres of excellence nationwide, including UCL Institute of Neurology, University of Oxford, King's College London and Plymouth University.

In addition, to reflect our expanded charitable objects, we have adopted the working name Brain Research UK to strengthen further our national identity.

With your help, we can continue to accelerate the progress of neurological research and improve the lives of those affected. Thank you.



Jonathan Kropman
Chair of Trustees



Our research

Our research priorities

We are currently funding research into a wide range of conditions including neurodegenerative disorders such as Alzheimer’s disease and Parkinson’s disease, epilepsy, stroke, brain tumours, motor neurone disease and ataxia.

In 2016, our Scientific Advisory Panel identified three priority areas where they considered research investment was most needed. In each of these three areas, set out below, they highlighted a large unmet patient need coupled with lack of current research investment.

Acquired brain damage

Acquired brain damage is caused by an injury to the brain after birth. Such injury may be traumatic or non-traumatic.

There are around 350,000 hospital admissions every year in the UK relating to acquired brain injuries. Whilst the outcome of an injury depends largely upon its nature and severity, many people require long-term rehabilitation in order to maximise function and independence.

We are funding research to advance understanding of how to promote repair of the brain. This may be through behavioural interventions that stimulate recovery, or medical interventions, or a combination of both.

Neuro-oncology

Brain tumours kill more under 40s than any other cancer.

Every year in the UK 11,000 people are diagnosed with a brain tumour, and 5,000 lives are lost.

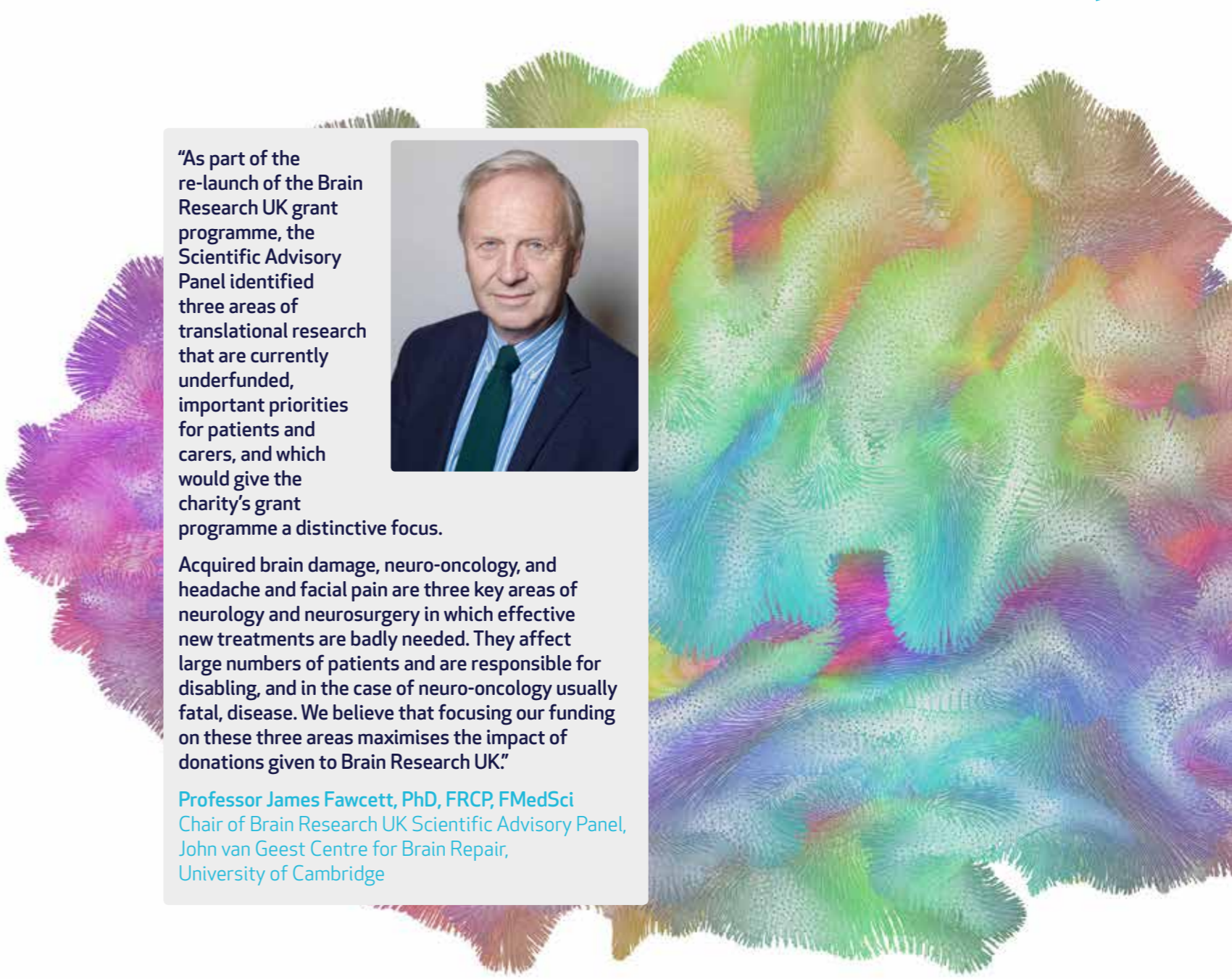
With more than 130 different types of brain tumour, which may all present with different types of symptoms, they are difficult to diagnose and exceptionally difficult to treat.

We want to improve the outlook for people with brain tumours by funding research that takes forward our understanding of the mechanisms underlying tumour development and helps develop better ways to diagnose and treat these tumours.

Headache and facial pain

Headache has been described as the most common medical complaint known to man. There are hundreds of different types of headache and facial pain disorders, ranging enormously in severity and in the impact that they have on people’s lives.

We want to relieve the impact on people’s lives by funding research that addresses the causes and mechanisms of headache and facial pain, and advances diagnosis and treatment of these disorders.



“As part of the re-launch of the Brain Research UK grant programme, the Scientific Advisory Panel identified three areas of translational research that are currently underfunded, important priorities for patients and carers, and which would give the charity’s grant programme a distinctive focus.



Acquired brain damage, neuro-oncology, and headache and facial pain are three key areas of neurology and neurosurgery in which effective new treatments are badly needed. They affect large numbers of patients and are responsible for disabling, and in the case of neuro-oncology usually fatal, disease. We believe that focusing our funding on these three areas maximises the impact of donations given to Brain Research UK.”

Professor James Fawcett, PhD, FRCP, FMedSci
Chair of Brain Research UK Scientific Advisory Panel,
John van Geest Centre for Brain Repair,
University of Cambridge



Our research

Our new research projects

Since launching our first national call for project grant applications in January 2017, we are delighted to have awarded funding of £881,688 for three new and exciting research projects.

The three projects were carefully selected from 32 applications received, following rigorous assessment by our Scientific Advisory Panel with input from dozens of external reviewers. The three successful applications were scientifically compelling and each stands to make an important contribution to knowledge in an important area with high unmet need.

Dr Claudia Barros

of Plymouth University was awarded a grant for her study of the mechanisms underlying formation of the brain tumour glioblastoma.

Glioblastoma is the most common primary malignant brain tumour in adults. Its impact is devastating – there is no cure and most patients die within a year of diagnosis. Dr Barros will be studying the cancer stem cells within glioblastoma. These are thought to drive tumour recurrence after treatment. Little is known about the properties of these stem cells but they may hold the key to the development of new and more effective treatments for glioblastoma.

Dr Lawrence Moon

of King's College London was awarded a grant to develop his gene therapy approach for promoting recovery after stroke.

Many stroke survivors are left with disabilities that limit their ability to live a productive, independent life. Improving stroke recovery is therefore a key goal. Dr Moon is using a form of gene therapy designed to improve recovery in stroke patients by enhancing the brain's remarkable ability to 'rewire' itself. The therapy, which will be used in combination with physical therapy, will have relevance for people with other types of brain damage, beyond stroke.

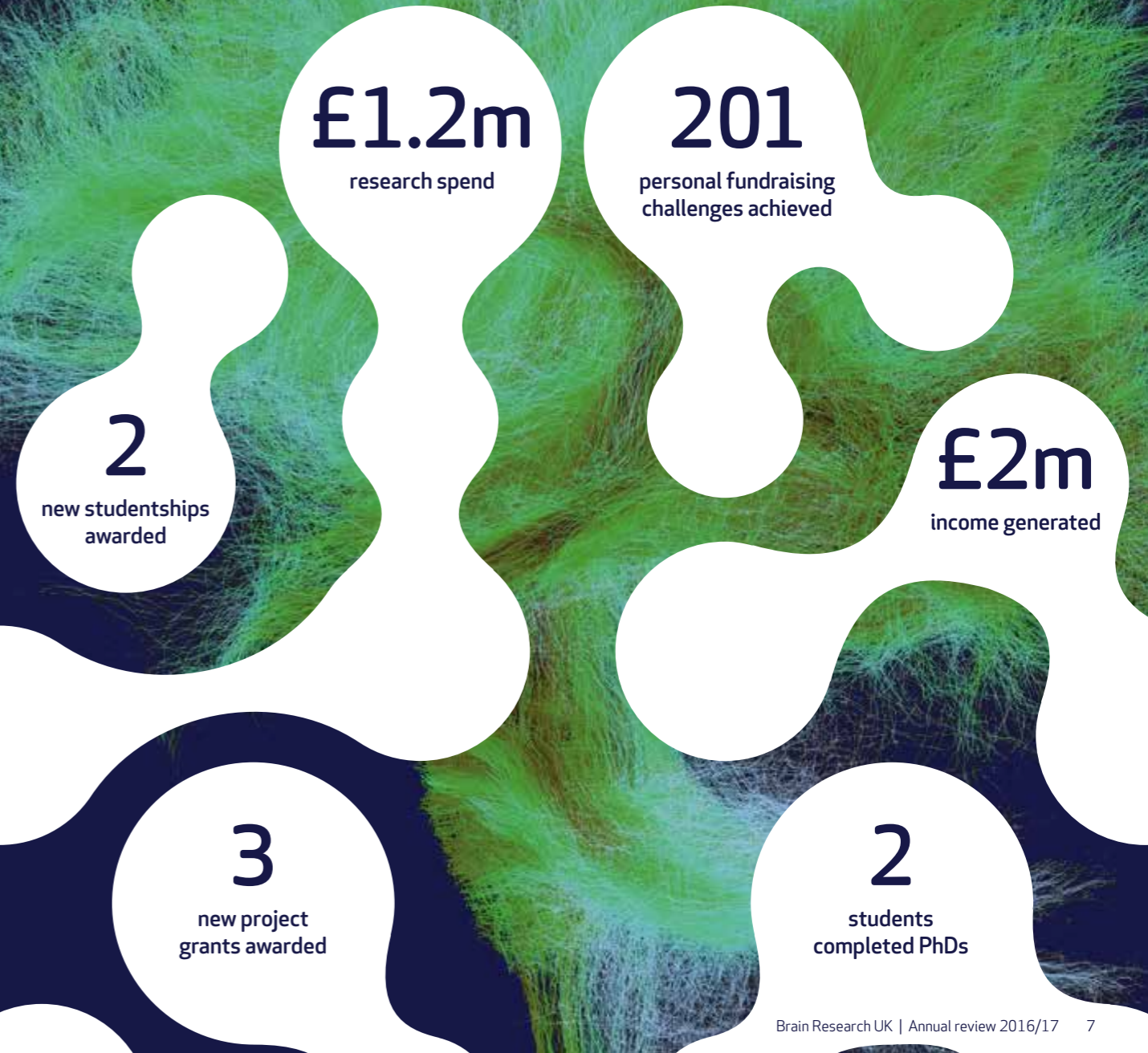
Professor Sven Bestmann

of UCL Institute of Neurology, has been awarded funding for his work on non-invasive brain stimulation for enhancing recovery after stroke.

Electrical brain stimulation is becoming widely used as a tool to promote recovery of the brain after injury. Results have been mixed due to inconsistencies in the way that the technique is used. Professor Bestmann will use cutting edge techniques to make sure that the right amount of electrical current is delivered to the right part of the brain, helping to unlock the full potential of brain stimulation to promote recovery after stroke.



Our impact 2016/17



Funding research



PhD studentships

PhD studentships nurture the development of promising researchers who we hope will go on to develop long and illustrious careers in brain research, becoming the next generation of research leaders to help all those with neurological conditions. In this way we are investing in the future of brain research.

This year, funding was awarded to two talented young scientists:



Richard Baugh:
University of Oxford

Richard's PhD research focuses on glioblastoma, a devastating brain tumour that has survival times close to the worst of any cancer. Richard is working on the development of a new immunotherapy approach to target glioblastoma.



Dr Emer O'Connor:
UCL Institute of Neurology

Emer's PhD research focuses on cluster headache, a condition so painful and debilitating it is commonly known as 'suicide headache'. Emer is studying the genetics of cluster headache in work that will ultimately help guide the design of new therapies for this condition.

Two Brain Research UK-funded PhD students completed their studies at UCL Institute of Neurology this year:



Camilla Nord: The use of electrical brain stimulation as a treatment for depression

Camilla carried out a number of studies on the effect of electrical brain stimulation, comparing its effects to antidepressant medication, and looking at how it works in conjunction with conventional psychological therapy. She also used brain imaging techniques to study activity in the area of the brain that is targeted by this electrical stimulation.

One of her most important findings was that she could use brain imaging to predict which patients would show the greatest benefit from brain stimulation. This is the first biomarker discovered in a clinical trial for electrical brain stimulation and is a discovery that – subject to replication – could be used in the clinic to enable personalisation of therapy.

Camilla has now taken up a post-doctoral appointment in the Department of Psychiatry at the University of Cambridge.



Dr Roman Prashberger: Understanding the mechanisms of *GOSR2*-mediated progressive myoclonus epilepsy

GOSR2-mediated progressive myoclonus epilepsy (PME) is a severe epilepsy syndrome caused by a mutation in the *GOSR2* gene. It is characterised by an early disease onset, at around three years of age, and core neurological symptoms including lack of motor co-ordination, muscle jerks, and generalised epilepsy.

Roman set out to investigate the mechanisms underlying this poorly understood disease. His research has provided a mechanistic understanding of this devastating form of epilepsy, and the process by which the underlying genetic mutations cause the neuronal damage that gives rise to its symptoms. As well as its relevance to PME, Roman's insights into the cell biology of neurons have potential relevance for other neurological diseases.

Roman embarked upon this PhD having previously qualified as a medical doctor. In pursuit of his intended career as an academic neurologist, he is now taking up a neurology training post at the University Hospital of Tübingen in Germany, where he will have 50% of his time available to pursue research.



Jonny's story

“Approximately four years ago my life changed beyond recognition. Not through an injury or a disability anyone could see, but by crippling headaches. These shattered me as a person and almost tore my family apart.”

Jonny, 40, from Yorkshire was diagnosed with the debilitating condition, chronic cluster headache four years ago.

“I kind of noticed that I’d had a funny headache for a while. As the pain increased and it began to bother me more, I went to get my eyes checked. The eye test was all clear and the optician referred me to a doctor. The doctor said it was possibly a migraine and put me on strong Ibuprofen.

However, over the next few months, on top of the constant “mild pain”, I kept getting “attacks” of excruciating pain where it felt like my eye was going to burst out of my head. I felt hot, sweaty, dizzy and sick. I couldn’t sleep and I would cry constantly. My eyes streamed and my nose would either be blocked or runny. I went back to the doctor, and was referred to a neurologist who was quick to diagnose me with chronic cluster headache.

Being in constant chronic pain is incredibly lonely. You can see people either don’t believe you, don’t really care or are frustrated because they can’t help. It is exhausting pretending everything is ok. It is heart-breaking seeing your kids so happy to be spending time with you to then watch their disappointment as you try to explain that your head hurts too much to even move. It feels like a bad joke. I could see it in myself that I had changed from being bright, academic and fun to slow, sluggish and grumpy all the time. I was falling behind at work and I had to leave the band I loved.

After seeing my neurologist regularly for two years they diagnosed me more specifically, tailored my medication and slow progress has been made in managing my illness. Although I still have days where the pain is so severe I vomit and can’t move, I’m

now the best I’ve been since this all started. I started running shortly after my diagnosis, and in April 2018 I will be running the Virgin Money London Marathon and raising funds for Brain Research UK. My goal is to make even the tiniest difference to the lives of other sufferers.”



Cluster headache affects one in 1,000 people and there is currently no cure.

Dr Emer O’Connor was awarded a Brain Research UK PhD studentship in 2017 to enable her to pursue her research in cluster headache. Emer first encountered patients with cluster headache as a junior doctor and was struck by its terrible impact. She was determined to do something to help.

As Jonny (left) knows only too well, cluster headache impacts heavily on the lives of patients. The all consuming pain and unpredictability of attacks can make it hard to carry on a normal life. The intensity of the pain is often reported to lead to suicidal thoughts, giving rise to the name of “suicide headache”.

But whilst there are a number of treatments that aim either to stop the pain during an attack or to stop the onset of attacks during a cluster, there is no cure. To work towards a cure, we first need to advance our understanding of the causes of cluster headache.

People with close relatives with cluster headache have an increased risk of developing it themselves, suggesting an underlying genetic cause. Emer is working in collaboration with an international network of headache specialists to examine this genetic basis. The team has assembled the largest cohort of cluster headache patients described to date and will use this unique resource to study the heritability of the disorder and identify and examine the genes responsible.

This project addresses a major knowledge gap concerning a disorder that is rare but has a devastating impact and will ultimately aid efforts to design new therapies for people like Jonny.



Anthony's story



Five-time Chelsea Flower Show Award winner Anthony decided to hold a plant sale in support of Brain Research UK because of the impact motor neurone disease (MND) has had on his life:

"The main reasons I support the work of Brain Research UK are entirely personal and certainly very emotional. I have lived through the deterioration of my father through MND until his early death at the age of 61, and it is hard to think of anything more distressing to experience from the outside than watching this happen to a loved one, but worse still must be to go through it oneself; just imagine how unbearable it must be to have an active mind and watch your body refuse to obey instructions and gradually wither away with what is effectively a death sentence. My father was an

extremely talented pianist, having trained in Paris, and etched on my mind is his devastation when he realised that he could no longer move accurately up and down the keyboard because his lower body refused to respond.

My overriding wish is that no-one should have to suffer as my father did, nor do I want anyone to have to witness his pain as I have."

Anthony is the second generation of his family to fundraise for Brain Research UK, as his mother raised a substantial amount of money through plant sales and coffee mornings for almost 25 years after his father's death.

Anthony raised an incredible £3,070.50 from his plant sale which took place in May 2017.



Professor Linda Greensmith and motor neurone disease

Professor Greensmith leads the Graeme Watts Laboratory at UCL Institute of Neurology in London.

She founded the Lab in 1999, supported by funds left to Brain Research UK by the family of Graeme Watts who was lost to motor neurone disease (MND).

The Graeme Watts Lab is now at the forefront of research into MND. They have the UK's best grouping of basic scientists working on MND and benefit from close collaborations with their clinical colleagues at The National Hospital for Neurology and Neurosurgery.

Their research has taken forward understanding of MND and how it develops, giving crucial clues as to how it can best be treated. They have shown that one of the key features of MND, like other neurodegenerative diseases, is a clumping of proteins in cells, in this case in the motor neurones. They have been targeting this process as a therapeutic strategy, and a drug developed in the Lab is currently undergoing clinical trial.

We continue to fund research in the Lab, using funds from the endowment established in Graeme's name.

"MND is such a dreadful disease. It's an unrelenting loss of muscle function, day after day after day. Every day is a bit worse than the day before. People live in fear of suffocating to death."

Professor Linda Greensmith, Head of Department of Motor Neuroscience and Movement Disorders, UCL Institute of Neurology



Fundraising highlights

There are many ways to raise money to help fund life-changing neurological research. Our amazing supporters do everything from running marathons, throwing themselves out of planes and walking The Great Wall of China to hosting quiz nights, shaving their beards and having coffee mornings. However it's done, whether £5 or £5,000, monies raised help to fund research that could change the life of someone living with a neurological condition.

Our amazing Virgin Money London Marathon team

► The Virgin Money London Marathon took place on 23 April 2017 and 45 runners were part of Team #BrainResearch. Together they raised an incredible £172,000 to help accelerate the progress of neurological research – the most ever raised from the marathon.

The team was full of incredibly inspiring runners, including Anthony who ran all 26.2 miles in a brain costume, raising £4,382; Michael, whose fundraising blog gained the attention of the London Marathon office and gave him the opportunity to run with a GoPro, raising £7,383; and Kenny, who ran in memory of a close friend and raised £8,207 – this is in addition to the more than £4,000 he raised for us when running the Virgin Money London Marathon in 2013.



Fundraising highlights

Ultra-marathon across the Alps

► In September 2017, George completed the UTMB CCC 100km ultra-marathon across the Alps and raised an incredible £14,121 for Brain Research UK. The challenge had to be completed within 27 hours and the race scaled over 6,500m of ascent and crossed three different countries.

“The brain remains one of the last frontiers of medical research, with it ever more likely that a number of us will have a serious neurological condition as life expectancies increase. Given I have seen the challenges of solving neurological disorders first hand, I really believe in raising money to help drive further research across this field”.

George



More highlights

● Paula raised over £2,400 completing a five-day trek along the Great Wall of China. Paula had a close family member who died from sporadic Creutzfeldt-Jakob disease in 2014.

● Gerri completed the Prudential RideLondon 100 in memory of her father, who passed from a neurological condition. She raised a fantastic £4,100 for Brain Research UK.



▲ Natasha organised a sponsored walk around St Ives in Cambridgeshire. There was a total of 70 walkers, participating in memory of Natasha's mum, who sadly died last year after living with sporadic Creutzfeldt-Jakob disease. Natasha's walk raised over £3,500.

Fundraising highlights



More highlights



◀ Simon undertook a series of events to raise money for Brain Research UK after his friend was diagnosed with a brain tumour. The events started with the Virgin Money London Marathon in April, and then four Swedish events including a 300km bike ride, a 3km swim, a 30km trail run and a 90km cross-country ski race. He has raised over £500 to date.

● £415 raised by residents and staff at Adderley Green Care Centre.

● £127 raised by Georgina & Mark in celebration of their wedding.



◀ Jack, 21, was diagnosed with the genetic disorder Huntington's disease when he was 18, and ran the Virgin Money London Marathon 2017 for us along with his mum, Juliette. They held a ball as part of their fundraising and together they raised an absolutely wonderful £31,609.

A big thank you

A sincere and heartfelt thank you to everyone who has so kindly supported us over the last year.

Whether you ran a marathon, took part in an event, volunteered your time, shared your story, generously donated or gave a gift. For all that you have done, thank you.

It is only with your support that we are able to accelerate the progress of brain research, improving the lives of people with a neurological condition.

We thank the following for their special and generous contribution:

- Simon Carter
- Jack May
- Kenny McAlpine
- George Moss
- Juliette Noble-Jones
- Michael Nollet
- Laura Pani
- India Wilkinson, aged 19, greatly valued and much missed having lost her fight to a brain tumour in December 2017
- The James Weir Foundation
- The Rene Horton and Joan Parkin Charitable Trust and Trustees

A warm thank you to everyone who has supported through volunteering their time, including:

- Our Scientific Advisors
- Our peer reviewers



Our performance



During 2016/17, as planned, we invested in the growth of our supporter donor base to develop sustainable, regular giving income. In addition, we diversified our fundraising streams and developed our activities, most notably within events as well as charitable trusts.

We launched, and concluded, our first national calls for PhD studentships and project grants.

Our remit as a national funder of neurological research was further enhanced with the adoption of Brain Research UK as our working name.

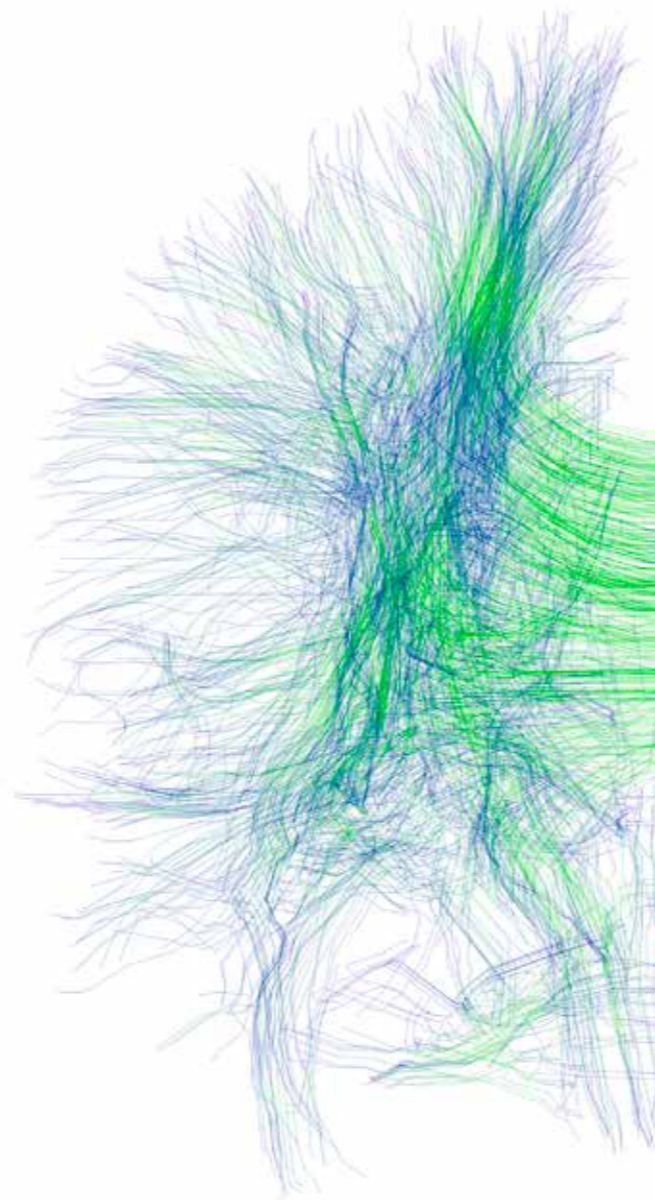
Our objectives for 2017/18 are:

Research:

- To continue our investment in leading edge neurological research to the increased benefit of all those with a neurological condition
- To continue our research investment in centres of excellence throughout the UK

Fundraising:

- To develop our event activities
- To develop our trusts fundraising activities



Our finances



	2017 £'000	2016 £'000
Our income		
Individuals	750	824
Trusts, corporates and major donors	154	352
Income from events	283	229
Legacies	321	631
Donations	1,508	2,036
Investment income	490	574
Total income	1,998	2,610
Our expenditure	2017 £'000	2016 £'000
Raising funds	1,023	1,724
Charitable activities	1,686	2,456
Total expenditure	2,709	4,180

This summarised financial statement was extracted from the full trustees' annual report and financial statement which was approved by the trustees on 7 December 2017. The full financial statements, on which the auditors haysmcintyre gave an unqualified audit report was submitted to the Charity Commission and to the Registrar of Companies.

The auditors have confirmed that, in their opinion, this summarised statement is consistent with the full statement for the year ended 30 September 2017.

The full trustees' annual report and financial statement and auditors report may be obtained from Brain Research UK, Dutch House, 307-308 High Holborn, London WC1V 7LL or brainresearchuk.org.uk

Together we can accelerate
the progress of brain research

Please support us by donating,
volunteering or fundraising.





Front and back cover images:

Image: computer enhanced electromagnetic image
courtesy of M. Chamberland and M. Descoteaux from
the Sherbrooke Connectivity Imaging Lab (SCIL)
(<http://scil.dinf.usherbrooke.ca>).

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