

Inspiring progress, together



Brain Research UK  
Annual review 2017/18



# 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.





# Welcome to our annual review



**Jim Gollan**  
Chair of Trustees

One in six of us has 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.

We receive no government funding and it is only thanks to the generosity of our supporters that such vital life-changing, life-saving neurological research can be funded.

In 2017/18, we continued our commitment to three priority research areas: neuro-oncology, acquired brain and spinal cord injury, and headache and facial pain. I am delighted to report that we awarded funding of close to £4 million, our highest ever annual investment in research.

Our commitment to the progress of neurological research to the benefit of all those affected is as resolute today as it was when we began in 1971.

Too many of us are touched by these devastating conditions. My heartfelt thanks to everyone who has so kindly supported our work. I look forward to all we can continue to achieve together in the future.



# Our research

## Three priority areas

Our research funding is currently focused on three priority areas where we consider research investment is most needed. In each of these three areas, set out below, there is large unmet patient need and insufficient research investment.

2017/18 was our second year focusing on these priority themes. We were pleased to receive a large number of high quality applications under both our project grant and our PhD studentship schemes.

In assessing the applications, the members of our Scientific Advisory Panel sought input from dozens of external reviewers to help guide their decision-making.

We are grateful not only to the hard-working members of our Scientific Advisory Panel but also to the many external reviewers who have freely given their time to help ensure that we fund the very best research.

### Acquired brain and spinal cord injury

There are more than 500,000 people in the UK living with long-term problems as a result of a traumatic brain or spinal cord injury. In addition, there are hundreds of thousands more people living with the effects of non-traumatic injuries, such as stroke.

The outcome of any injury to the brain or spinal cord depends largely upon its nature and severity but, despite long-term rehabilitation, many people do not regain full function.

We are funding research to advance understanding of how to promote repair of the brain and spinal cord and thus restore function and independence.

This year, we have funded two projects and one studentship under this priority area – with grants to Professor Nick Ward, page 6, Professor Simone Di Giovanni, page 7, and Franziska Mueller, page 8.

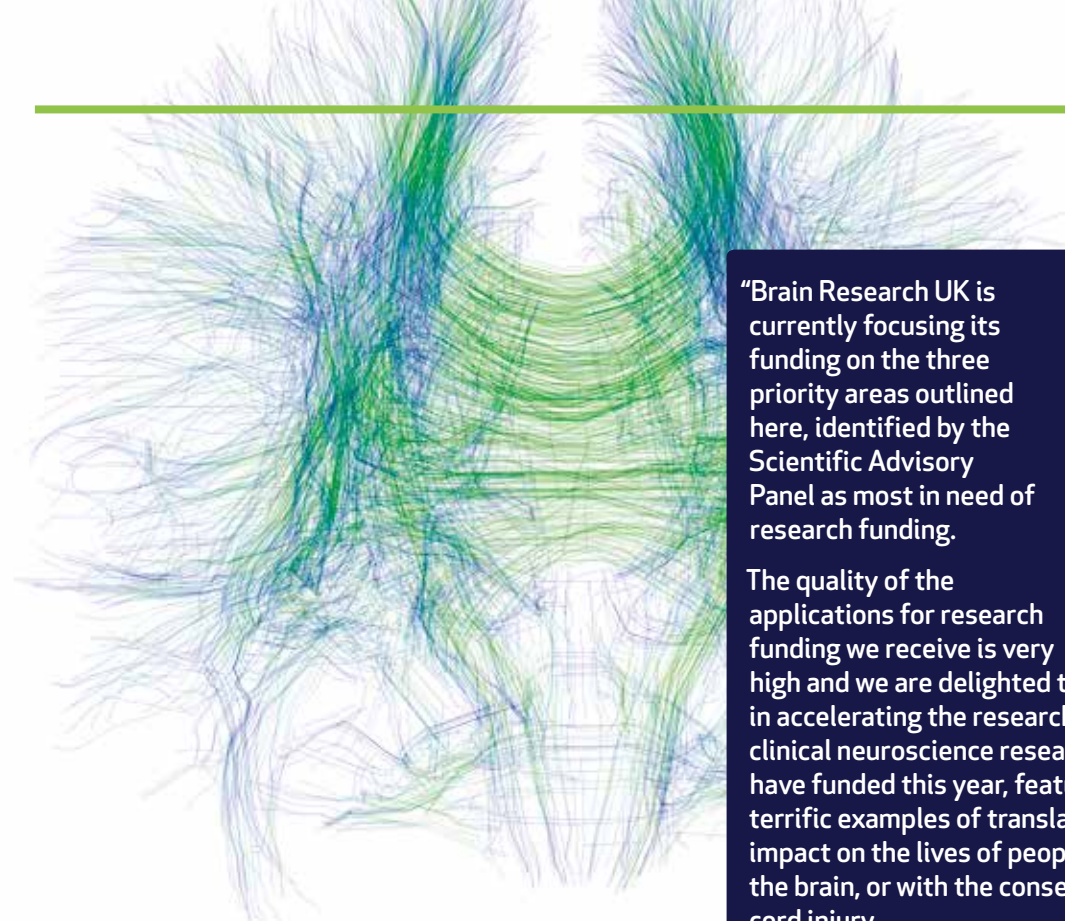
### Brain tumours

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 at least 130 different types of brain tumour, which may all present with different symptoms, their diagnosis and treatment is extremely difficult.

We want to improve the outlook for people with brain tumours by funding research that takes forward our understanding of tumour development, and advances diagnosis and treatment.

This year, we have funded one project and one studentship focused on brain tumours – with grants to Professor Chris Jones, page 6, and Rhiannon Barrow, page 8.



“Brain Research UK is currently focusing its funding on the three priority areas outlined here, identified by the Scientific Advisory Panel as most in need of research funding.



The quality of the applications for research funding we receive is very high and we are delighted to be able to play a role in accelerating the research of some of the UK’s top clinical neuroscience research teams. The projects we have funded this year, featured on pages 6 and 7, are terrific examples of translational research with direct impact on the lives of people living with diseases of the brain, or with the consequences of brain or spinal cord injury.

The three successful studentship applicants featured on page 8 are young scientists with outstanding potential. We are confident that they will succeed in their planned research and will go on to become future leaders in brain research, strengthening the UK’s capacity in this critical area.

We look forward to following the progress of this research over the coming years.”

**Professor Kevin Talbot MB BS, DPhil, FRCP  
Nuffield Department of Clinical Neurosciences,  
University of Oxford  
Chair, Brain Research UK Scientific Advisory Panel**

### 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. Because of their prevalence, headache disorders rank as the sixth leading cause of disability globally.

This year, we have funded one project and one studentship focused on headache, with grants to Professor Peter McNaughton, page 7, and Oakley Morgan, page 8.



# Our research

## Our new research projects

We are delighted to have awarded funding of £1.1 million for four exciting new projects, carefully selected from amongst the many applications submitted under our annual project grant call. Following review by members of our Scientific Advisory Panel, short-listed projects also underwent scrutiny by external expert reviewers to inform final decisions. Each of the four successful projects stands to make an important contribution to knowledge in an area of high unmet need.

### ▼ Professor Chris Jones, The Institute of Cancer Research, London

Diffuse Intrinsic Pontine Glioma – DIPG – is a devastating childhood brain tumour. It develops in the brain stem, mainly presenting in children aged 5 to 10 years. There is no effective treatment and most children die within 18 months of diagnosis.

With our funding, Professor Jones is building on a previous body of work that has identified a key genetic mutation in DIPG tumours. The aim is to find a drug that will target this mutation and kill the tumour cells.

We hope that this project will lead into a clinical trial of new drugs, offering hope to families affected by DIPG.



### ▲ Professor Nick Ward, UCL Queen Square Institute of Neurology

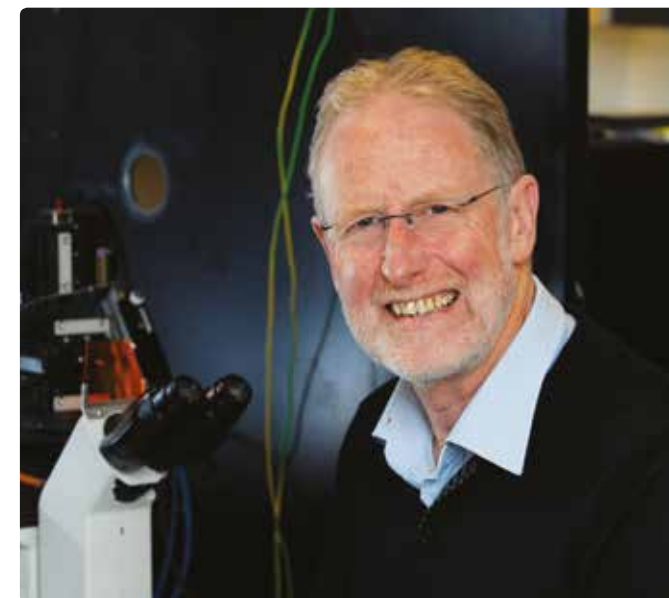
Stroke is the most common form of brain injury and one of the leading causes of disability worldwide. Some patients with initially severe impairments recover quickly, whilst others do not recover. It is not clear why.

Professor Ward is using neuroimaging to determine whether these different recovery trajectories can be explained by differences in patterns of anatomical brain damage and early post-stroke brain repair mechanisms.

This work, which is being carried out for the first time anywhere in the world, will help to determine treatment pathways for individual patients, to enable them to make the best recovery.



### ▼ Professor Simone Di Giovanni, Imperial College London



Damage to nerves in the spinal cord is irreparable and severe injury causes serious, permanent disability. In contrast to the nerves in the spinal cord, nerves outside the spinal cord (peripheral nerves) can regenerate following injury.

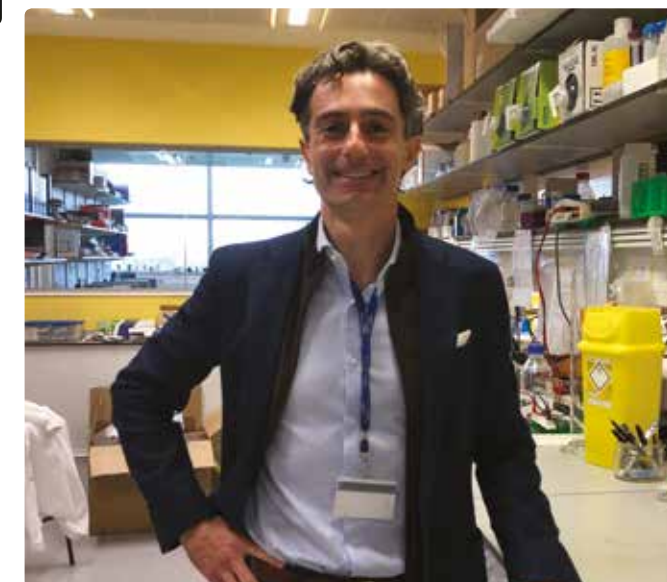
Working with collaborators in Switzerland, Professor Di Giovanni is studying the complex mechanisms underlying this peripheral nerve regeneration to understand how the mechanisms can be exploited to promote the repair of nerves within the spinal cord.

The team will apply the results of this research to test different techniques in the repair of spinal cord injury. This will underpin efforts to develop interventions that can promote repair of the spinal cord and enable people with spinal cord injuries to recover function.

### ▲ Professor Peter McNaughton, King's College London

Migraine is a debilitating condition with a variety of symptoms, most notably a painful headache. It affects more people than diabetes, epilepsy and asthma combined. Existing treatments can reduce the severity of attacks in some people and steps can be taken to reduce the likelihood of attacks occurring, but many sufferers struggle to achieve effective relief.

Professor McNaughton is looking at the processes that drive the pain in migraine, with the aim of opening up new ways to target them therapeutically. If successfully developed, this could have a major impact on treatment for patients suffering from this common disorder.







# Funding research

Through our PhD studentships we aim to nurture the development of promising researchers, who will go on to enjoy long and illustrious careers in brain research. In this way, we are building research capacity in our priority areas and investing in the future of brain research.

This year, we were able to award funding to three, rather than two, talented young scientists. This was made possible by the significant amount raised by Team #BrainResearch in the London Marathon 2018.



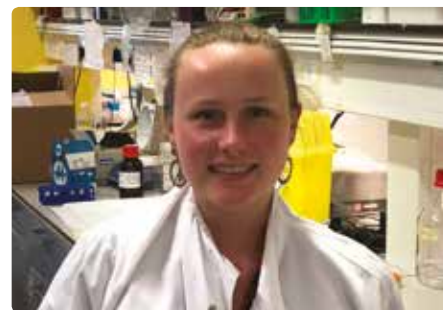
**Rhiannon Barrow,  
University of Leeds:**

Rhiannon's research is focused on the brain tumour glioblastoma, an aggressive tumour that is often resistant to treatment so quickly recurs. Rhiannon is trying to unravel the mechanisms underpinning treatment resistance so that we can find new ways to attack the tumour and improve the outlook for those affected by this devastating tumour.



**Oakley Morgan,  
University College London:**

Oakley's PhD research focuses on the complex relationship between stress, facial pain disorders and headache. Migraine and facial pain are two of the most common and debilitating pain conditions, and our limited knowledge of the underlying causes of these conditions makes them difficult to manage. Oakley hopes that the insight gained through her research will contribute to the development of more effective treatments.



**Franziska Mueller,  
Imperial College London:**

Franziska is focusing on spinal cord injury and how to promote the regrowth of severed nerve fibres in the spinal cord. She is taking forward work that has previously found a way to switch on genes that stimulate some regrowth of severed nerve fibres, and combining this with neurorehabilitation. This will help build the evidence needed to take this combined approach forward to clinical trial.



## Completed studentships:

### Thomas Moens completed his PhD at UCL Queen Square Institute of Neurology in 2018.

**The mechanisms of toxicity of a genetic mutation common to motor neurone disease and frontotemporal dementia.**

Amyotrophic lateral sclerosis (ALS) is the most common form of motor neurone disease, whilst frontotemporal dementia (FTD) is the second most common form of dementia, after Alzheimer's disease. In recent years, scientists have found evidence that these two diseases are linked.

In 2011, it was discovered that the same genetic mutation, which occurs in a gene known as *C9orf72*, is the most common genetic cause of both ALS and FTD. In his PhD project, Thomas set out to understand how this mutation causes the damage that leads to the development of these diseases.

He worked as part of a team that demonstrated that the mutation gives rise to the formation of toxic protein molecules, and has since completed further work assessing how this toxicity occurs.

His work – which has given rise to six published papers - gives important new clues as to the causes of these two devastating diseases and insight into possible new ways to treat them.

Since completing his PhD, Thomas has taken up post-doctoral research at VIB-KU Leuven Center for Brain & Disease Research in Belgium. He has recently been awarded a prestigious Marie Curie Fellowship, which will allow him to continue his study of the mechanisms underlying ALS and FTD.



## Jo's story

Jo was 22 when a stroke changed her life forever. This happened without warning, whilst cycling in the Highlands.

Her stroke affected her ability to speak, to read and write, to communicate with her loved ones and to fully make sense of the world around her.

"For the first few weeks I didn't understand what was going on. I think my family and friends found the first few days particularly traumatic."

Jo spent the next three years rebuilding her life. She spent the first year having speech therapy so that she could fully communicate with those around her. However, a further blow came just six months into recovery, when she was diagnosed as suffering with post-traumatic stress as a result of the stroke.

In the following years, at a time when her friends were starting their careers, meeting new friends and living carefree lives, Jo was in and out of hospital and receiving counselling. Against all the odds, Jo returned to full-time work 14 months after her stroke and was given the "all clear" after three years.

Incredibly, she and her husband ran the London Marathon in April 2018, raising £8,652 for Brain Research UK.

Jo will never forget how her stroke changed her life nor the months of speech therapy and the years rebuilding her life.

Following recovery, Jo completed a Masters degree in Neurological Physiotherapy and now works as a Neuro Physio in Nottinghamshire helping others who are coping daily with the effects of a stroke.

"When you have a stroke, your world changes and you feel like it is at an end. I want to help encourage others with neurological conditions that their goals can still be achieved."

Jo's story has a happy ending. However, many of those affected by stroke fare less well.

Whilst, thankfully, more people are surviving stroke than ever before, this means that there is an increasing number of people living with the after-effects of stroke. There are an estimated 1.2 million stroke survivors in the UK today, two thirds of whom leave hospital with a disability.



The range of disabilities associated with stroke is greater than for any other condition and includes limb weakness, and problems with vision, language and communication. Extreme fatigue is also a common side-effect, with depression and anxiety also common.

We are funding research to advance understanding of how to repair the damage caused by stroke and other forms of brain and spinal cord injury, to enable maximum recovery and improve the lives of those affected.



## Investigating spontaneous early recovery after stroke: why do some patients recover whilst others do not?

We awarded project funding to Professor Nick Ward of UCL Queen Square Institute of Neurology to enable him to examine different recovery trajectories between stroke patients.

He explains his project:

"I've always been interested in brain plasticity, the idea that the brain can change structure and therefore function in response to the environment or to some form of training. Plasticity is the most fundamental property of the brain and therefore, as neurologists, we have to be interested in it when thinking about improving brain function in our patients. Stroke is the commonest form of brain injury and one of the commonest causes of disability worldwide. Understanding plasticity mechanisms will help us improve outcomes for stroke patients."

His research uses neuroimaging to study the post-stroke brain, and the changes to structure and function.

"We have shown that the reorganisation of surviving brain regions into new networks is important for supporting recovered



function. In fact, some brain regions take on new roles in helping patients recover movement.

"However, the mechanisms underlying this process are not clear. In this project, we will look at the differences between good and

poor recoverers to reveal which factors are important for recovery itself. It is possible that the extent of the anatomical damage might set a limit on recovery, but also that the emergence of an increase in the potential for plasticity provides an opportunity for maximising recovery.

"We will use a brain imaging technique called magnetoencephalography (MEG) to measure how brain waves are changed after stroke. We believe that the strength of these brain waves will indicate whether the potential for plasticity (and therefore learning and recovery) is increased or decreased after stroke.

"We can then think about using drugs to alter these brain waves (and therefore plasticity) so that patients respond better to rehabilitative training, so maximising their recovery.

"This funding will allow us to start this work for the first time anywhere in the world."



# Ed and James climb Mount Elbrus

In July 2018, Ed and James climbed Mount Elbrus, the highest mountain in Europe, located in the Caucasus Mountains on the Russian/Georgian border. At 5,642m (18,510 ft), Elbrus is one of the coveted “Seven Summits” – the highest mountains on each of the continents – and is the tenth most prominent mountain in the world.

This challenge pushed them to their mental and physical limits. They were spurred on by their aim of raising £10,000 for neurological research, due to the many personal links they have with neurological conditions.

They both have close family members affected by stroke, brain tumours and Alzheimer’s disease.

With 12 months of fundraising, ranging from hosting dinner parties and BBQs to networking events and office cake sales, and their exhaustive training, which consisted of endurance strength conditioning and cardio based circuits as well as weighted runs and climbs in the Lake District, their commitment and determination was incredible.

Through their hard work and dedication, Ed and James raised a staggering £11,011 for Brain Research UK.







# Professor Rob Brownstone, Brain Research UK Chair of Neurosurgery, UCL Queen Square Institute of Neurology

Professor Brownstone moved to London from his native Canada in 2015, to take up the post of Brain Research UK Chair of Neurosurgery at UCL.

This new post was created as a result of a partnership between the Institute of Neurology and Brain Research UK to develop and promote neurosurgical research at UCL.

As a functional neurosurgeon, Professor Brownstone has focused on quality of life neurosurgery, treating patients with, for example, disorders affecting movement or leading to intractable pain syndromes. In his lab, he combines electrophysiological and imaging techniques with mouse genetics to understand motor circuits, with a goal of developing new strategies to improve movement in neurological disease or following injury. His research is funded by a Wellcome Trust Investigator Award. He is a Fellow of the Canadian Academy of Health Sciences.

Professor Brownstone's focus is to understand how the brain and spinal cord work together to ensure that the intended movement accomplishes the task at hand. Further, he studies how these motor circuits are affected by neurological conditions, and aims to develop strategies so that the function of these circuits can be restored. As movement is affected in so many neurological conditions, his research programme has the potential for widespread impact.



“Whether your movement is impaired because of a stroke, multiple sclerosis, spinal cord injury, Parkinson’s disease, dystonia, or one of numerous other neurological conditions, improving movement will give you a better quality of life.

“Two aspects in particular that I study are how we walk, and how our hand function works. How are our muscles activated at exactly the right time and in exactly the right order so that we can get from point A to point B? How can we perfectly pick up a paper cup or a ceramic mug so that we don’t squish the paper cup or drop the ceramic mug? These are functions that we take for granted, until we lose control of them.”

**Professor Rob Brownstone**



# Fundraising highlights

There are many ways to raise money to help fund life-changing neurological research. Our amazing supporters do everything from running marathons, cycling from Land's End to John O'Groats 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 to change the life of someone living with a neurological condition.

## Our fantastic Virgin Money London Marathon Team

▼ The Virgin Money London Marathon took place on 22nd April 2018. We were thrilled to have our largest ever team with 145 runners braving the heat on the day as they ran from Blackheath to Buckingham Palace as part of Team #BrainResearch. Together, an incredible £520,000 was raised to help accelerate the progress of neurological research – the most the charity has ever raised from the marathon. An amazing achievement of which all involved deserve to be enormously proud!



## Charlotte's story

▶ Charlotte ran the London Marathon 2018 to support others who have been affected by neurological conditions.

"In 2014, aged 28, I suffered a carotid artery dissection and pseudo-aneurism stroke. It was an incredibly life changing event for myself, my family and friends and since then I live my life to the maximum and have pretty much fully recovered with the exception of migraines on a continuous basis. The brain and neurological disorders are a cause very close to my heart and I wanted to run the marathon to show how far I have come and also raise awareness for the medical research that Brain Research UK fund"

Charlotte raised an impressive and inspiring £15,557 for Brain Research UK.



# Fundraising highlights



## Richard's story

▲ Diagnosed with an inoperable brain tumour in February 2017, and following a biopsy, radiotherapy and chemotherapy, Richard decided to dust off his running shoes and take part in his third London Marathon.

"After recovering from treatment for a brain tumour I wanted to set a personal target of running the marathon. I heard about the wonderful work carried out by Brain Research UK and thought I would try and fundraise. The experience did not disappoint. Training helped me recover mentally and physically. The fundraising allowed me to give back a little for future research."

We are enormously grateful to Richard and the three others on his team who raised a tremendous £21,335 for Brain Research UK.

## More highlights

▼ London-based law firm Fox Williams selected us as their Charity of the Year in April 2017, to show support for a colleague who was diagnosed with Motor Neurone Disease. They went on to hold countless fundraising activities in support of further neurological research, including a quiz night, fundraising breakfast, social evenings, raffles and wine nights. Through their hard work and dedication, they raised a fantastic £9,375.







# Fundraising highlights

## More highlights



▲ In October 2017, having just retired, Barbara was on the holiday of a lifetime touring China when she fell off a wall and suffered profound brain and spinal injuries. Following this devastating injury of their beloved sister, William and Alison decided to raise as much money as possible for neurological research, to help the thousands of people like their sister. Miraculously, after nine weeks in a coma, Barbara started to speak again ("Ouch, No more physio!" were her first words!) and has been able to move back home and gradually continue to gain her life back. William and Alison raised a wonderful £8,253 completing the London Marathon 2018.

● Students from Highsted Grammar School held a bazaar in December raising £30 for the charity.

▶ Julian completed the Coast to Coast Walk (some 192 miles) in memory of his brother Simon, who tragically passed away as a result of a brain haemorrhage at the age of 46. Only six months earlier, Julian had been best man at Simon and Julie's wedding. People special to Julian and his parents joined him on the walk, which lasted two weeks, raising an incredible £5,254 for the charity.



● Sally organised a black tie piano recital evening at her house to raise funds in May 2018. The evening raised a fabulous £1,779 for the charity.

● Kate and Brian cycled the entire length of the UK - from Land's End to John O'Groats - a distance of 1000 miles. Kate's father suffers from dementia and so she knows first hand the cruel devastating impact it can have on daily life. Kate and Brian also have several friends and colleagues who have suffered from or who have lost a loved one due to a variety of neurological diseases. They raised a superb £2,716.



# Thank you

**A sincere and heartfelt thank you to each and every one of the thousands of people who have so kindly supported us during the year.**

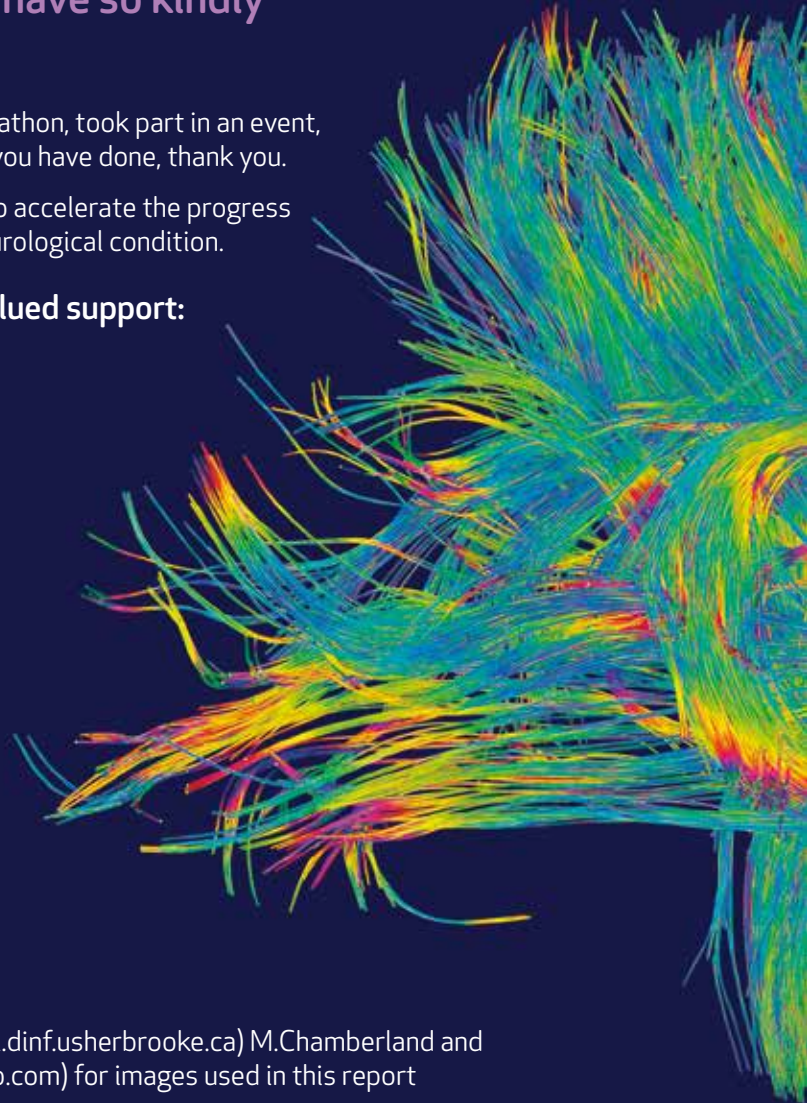
Whether you generously donated or gave a gift, ran a marathon, took part in an event, volunteered your time or shared your story... for all that you have done, thank you.

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

## **With special thanks to the following for their valued support:**

- Rachel Atwell, Claire Atwell-Dixon and Lorraine Brook
- The Back Family
- The Robert Barr Charitable Trust
- Ken Bossung
- Prof Rob Brownstone
- Prof Alasdair Coles
- Richard Cravitz
- Prof James Fawcett
- Sarah Gardner and Sarah Mills
- Prof Oliver Hanemann
- Prof Henry Houlden
- Hayley Smith
- Michael Nolle
- Our peer reviewers
- Dr Alexandra Sinclair
- The Sobell Foundation
- Prof Kevin Talbot
- Prof Nick Ward
- The William Allan Young Charitable Trust

We thank Sherbrooke Connectivity Imaging Lab (<http://scil.dinf.usherbrooke.ca>) M.Chamberland and M.Descoteaux and Science Photo Lab ([www.sciencephoto.com](http://www.sciencephoto.com)) for images used in this report







## Our performance

During 2017/18, we adapted our business model to enable more funds to be available for essential neurological research. We focused on developing our fundraising capabilities in events, particularly in the London Marathon. We were able to field our largest ever team resulting in an increase in our overall event income, from £283,000 to £654,000. This, together with additional income raised through legacies, has grown our total annual income from £1,998,000 to £2,329,000.

At the same time, we have actively managed a reduction in fundraising and overheads expenditure. Despite fundraising income rising, the cost of raising these funds has fallen by a third – from £1,023,000 to £687,000. Through operating more efficiently we have been able to generate increased funds available for research. Consequently, our spend on charitable activities during 2017/18, at £4,031,000, is our highest in one year and reaffirms our commitment to funding meaningful research.

### Our objectives for 2018/19:

As part of our strategic review, we are moving towards a different operating model that will be implemented fully during 2018/19. This includes a commitment to focus on core fundraising while operating a lean, agile organisation.

#### Our objectives for research activities:

- To sustain the amount of research and the impact of the research we fund
- To publish an updated Impact Report

#### Our objectives for fundraising:

- To develop our event and challenge activities
- To develop our major donor fundraising activities



# Our finances

	2018 £'000	2017 £'000
<b>Our income</b>		
Individuals	570	750
Trusts, corporates and major donors	145	154
Income from events	654	283
Legacies	454	321
<b>Donations</b>	<b>1,823</b>	<b>1,508</b>
Investment income	506	490
<b>Total income</b>	<b>2,329</b>	<b>1,998</b>
	2018 £'000	2017 £'000
<b>Our expenditure</b>		
Raising funds	687	1,023
Charitable activities	4,031	1,686
<b>Total expenditure</b>	<b>4,718</b>	<b>2,709</b>

This summarised financial statement was extracted from the full trustees' annual report and financial statement which was approved by the trustees on 7th March 2019. The full financial statements, on which our auditors haysmacintyre have given an unqualified audit report, were 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 statements for the year ended 30th September 2019.

The full trustees' annual report and financial statements and auditors report may be obtained from Brain Research UK, BWB Charity Hub, 10 Queen Street Place, London EC4R 1BE




Together we can accelerate  
the progress of brain research


Please support us by donating,  
volunteering or fundraising.



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