

**The National
Brain Appeal**
Funding advances
in neurology and
neurosurgery

Newsletter
Number 59
Autumn/Winter
2021

NEURO
MUSCULAR
BRAIN INJURY
STROKE
EPILEPSY
BRAIN TUMOUR
DEMENTIA
PRIOR
PARKINSON'S
MIGRAINE
SPINAL
MULTIPLE
SCLEROSIS

Groundbreaking
stem cell research

Stars support
Queen Square

Get ready
for ALIM21

THE NATION

MAJOR APPEAL



Professor Rickie Patani

The future of brain research

Work is well underway to create a new, state-of-the-art £281m neuroscience centre on Gray's Inn Road.

Bringing together research scientists, clinicians and patients, the Centre will be home to three organisations: the UCL Queen Square Institute of Neurology (IoN), the Dementia Research Institute Hub and the outpatient department of The National Hospital for Neurology and Neurosurgery. The work carried out here will benefit people across the UK and the world, searching for solutions to some of the most complex

problems affecting our brains and nervous systems.

The National Brain Appeal is funding three areas: a patient-research hub, two MRI scanners and a stem cell facility. Professor Rickie Patani and Professor Selina Wray will be co-leading this stem cell hub. We spoke to Professor Patani – a consultant neurologist at The National Hospital and Professor of Human Stem Cells and Regenerative Neurology at University College London and The Francis Crick Institute – about the project.

Why are stem cells so useful when it comes to neuroscience research?

They are invaluable because they solve a problem – we don't have easy access to the cell types that have gone wrong in neurological conditions. This means we either have to use cells that aren't from the nervous system or from humans, and these don't act in precisely the same way that the dysfunctional cells in a patient would. But patient-derived stem cells have the potential to grow into any kind of human cell – including complex types in the nervous system. This is great because we take a skin biopsy from a patient, 'transform' these into stem cells and then we can grow that patient's dysfunctional cells in a petri

dish. These can then be used to speed up the development and testing of new treatments and therapies for patients. We're touching the face of truly personalised medicine – which is very exciting.

What will be the main difference to the way you work once the hub is open?

It will be game-changing to have the co-location of clinical activity with fundamental science. This will drive the effort from 'basic science' discoveries into medical translation – and vice versa. If things are noticed within a group of patients, it can be fed back to scientists. This two-way exchange of information will be far more effective once we are all on site together. Clinicians will be able to take a skin biopsy from a patient, and a few months later we'll have their dysfunctional cells in a lab to work with! The new Centre will be the gold standard for neuro-disease modelling – it's the facility that is currently missing from stem cell research and will be transformational and unique.

What change are you most excited to see with the creation of the facility?

I'm most looking forward to having this core facility for stem cell differentiation because it will catalyse much of the

neuroscience research at Queen Square. At the moment, stem cell facilities are separate from the hospital – and are viewed as costly, time consuming and needing a lot of expertise. But this new facility will make working with stem cells far more accessible. Stem cells are incredible – they have the potential to become anything in the body. We give these 'master stem cells' guidance – like career advice – to coach them into ultimately becoming exactly the sort of cells we want to work with, such as very specific neurons that are dying in a patient with a certain neurological condition.

We can then witness and interrogate the exact moment that the onset of disease occurs. We can see what happened, when it happened and why it happened – and then tailor new treatments to slow it down, stop it or reverse it. It's why so many of us burn the candle at both ends to see these breakthroughs in medicine to help those living with devastating neurological diseases.

We need your support to fund this incredible new Centre. Please donate to this appeal at nationalbrainappeal.org/neuroscience

Letter from our Chief Executive



We know that it takes courage for people to share their own experiences of living with a neurological condition. It's so important that these brave voices are heard. Their stories help to improve understanding of how different conditions affect people and build awareness of the number of people affected – compared to the disparity in support available. It also attracts support to increase funding to provide hope for new treatments in the future.

Recently, two amazing people have stepped into the spotlight. Tom Parker, from band The Wanted, has made a documentary about his journey following a brain cancer diagnosis and has been highlighting the lack of clinical trials available. He also brought together an impressive line-up of artists at a concert at The Royal Albert Hall to raise funds for The National Brain Appeal and Stand Up to Cancer.

Sophie Leggett agreed to be the voice of our Radio 4 appeal and shared her experience of living with the fear that she may have inherited early-onset dementia and then how she coped when

it was confirmed that she had. The honesty of her account and her positive outlook is inspiring.

There's more about Tom and Sophie in this issue along with updates on the fundraising of so many others who have told the world about why they've been motivated to raise funds for us.

As more people have been hearing about these experiences, those who write fictional stories for the page, stage and screen have also been inspired to create characters affected, increasingly with leading actors cast to play them. This is so important as it starts the process of debate in a much wider audience. You will find information about three high-profile projects on p5.

One voice alone can often achieve a lot but the volume of all our voices together, factual and fictional, is invaluable for charities like us, who want the world to wake up to the need for more investment in neurological conditions. This will mean we can fund projects that make a difference for those who are living these real-life events and want to see happier stories.

Thanks to everyone who speaks up, whether in a whisper or a shout – every voice counts and you are making a real difference, every time.

Theresa

Theresa Dauncey, Chief Executive, The National Brain Appeal

MAJOR APPEAL

A unique centre for dementia

We are raising £7million to create the world's first centre of excellence for rarer dementias.

The Centre will draw on the hub of expertise already based at Queen Square. We talk to one of the leads on this project – Professor Sebastian Crutch.

What do you think will be the biggest impact that the new centre will have?

I hope the biggest impact will be on the quality of relationships between those living with or caring for someone with a rare dementia who use the space, and the team working with them. The support, learning and research parts of Rare Dementia Support (RDS) are all based on peers and professionals working together, so having a space designed to encourage equality between lived and professional experience will be exciting. We've very much been

inspired by Maggie's Centres for cancer care, and aim to create a welcoming, friendly space where people can feel at home.

How do you foresee it changing your current day-to-day job?

I think for anyone, having the right environment in which to fulfil the role you have been given is important. There are many amazing facilities around Queen Square where the physical properties of the space reflect the nature of the work that takes place within. The RDS team and I are really looking forward to being able to offer one-to-one, family and small group support in spaces that were actually designed to encourage and enable tailored emotional, social and practical support.

Professor Sebastian Crutch



The Centre will also help to stitch together the different parts of our work, and provide a seamless pathway for those living with dementia. For example, current and imminent successes in dementia research mean we need to prepare for higher numbers of people coming to Queen Square to

participate in ambitious, novel and genetic therapies. Having the Centre close at hand will allow us to offer integrated support for the people receiving those treatments and taking part in those trials.

RDS members will be able to do arts and cultural activities on the new site – how important is this?

Often the conversation around dementia is just about loss and limitation, while people's retained strengths, skills and interests get left behind. I've heard RDS members describe their creative lives and I can see how much enjoyment, purpose, meaning and anticipation they get from these activities. More importantly, people form powerful relationships and connections during group creative activities because it provides a safe space to get to know one another. The value of cultural activities is also not just for those directly involved – I've lost count of the number of family members, friends and carers who describe seeing the person they care for and about in a different light through the lens of creative activities. Words and images from the recent RDS online creativity club are available at raredementiasupport.org/creativity-club

Help us raise the first million for this vital appeal at nationalbrainappeal.org/RDS-Centre

Our six funding areas

We group our funding into six areas so you can see just how broad our reach is and where your money is going.

You can donate directly to a specific funding area if you choose to.

Find out more about our six funding areas by visiting our website: nationalbrainappeal.org/funding-areas



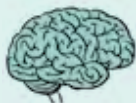
Queen Square
New facilities and staff-led projects at The National Hospital and the UCL Queen Square Institute of Neurology



Neurodegeneration
Supporting projects which help people with conditions where there is progressive degeneration



Neurosurgery
Providing state-of-the-art equipment and facilities for the UK's largest neurosurgery unit



Neurology
Funding initiatives to improve diagnosis, treatment and provide facilities for those with ongoing neurological conditions



Technology & Innovation
Supporting projects which translate ground-breaking ideas into better results for patients



Education & Staff Development
Investing to provide the best opportunities and attract the best people in the field



Technology and innovation Stroke care

Every five minutes someone in the UK has a stroke. For the most common type of stroke,

access to a thrombectomy procedure can lead to a full recovery in 50% of people. A thrombectomy involves using a specially-designed clot removal device inserted through a catheter to pull or suck out the clot to restore blood flow.

However, access to this life-saving treatment is being slowed by three challenges:

- 1 Specialist stroke centres don't always offer a thrombectomy.
- 2 The longer the delay in receiving a thrombectomy the less chance of complete recovery.
- 3 Patients being taken to the wrong treatment place, due to lack of diagnosis before arriving at hospital.

With the help of funding from our Small Acorns Fund, the National Hospital Stroke team piloted video-enabled pre-hospital triage with the London Ambulance Service last year. Patients were assessed via video calls once the ambulance arrived at the scene. This successfully diverted about half of people to other hospitals, people with 'warning' strokes to next-day clinics and improved thrombectomy treatment times at The National Hospital. Admissions of people with 'mimic' cases were reduced by 75%, and those who did arrive were people who needed specialist neurological care so were in the correct place. This initiative has since won a *Health Service Journal* Patient Safety Award.

To develop the idea further, the Innovation Fund is delighted to award a £50,000 grant to Dr Robert Simister to pilot a 'pre-ambulance' assessment in the North Central London area. Throughout the pilot, patients with a suspected stroke or TIA (mini stroke) will be linked with an online stroke specialist to be remotely assessed before the ambulance even arrives.

A successful pilot will ensure that stroke patients receive the right treatment faster and patients with serious neurological conditions are identified and offered specialist neurological care without delay.

The National Brain Appeal's Innovation Fund supports

projects that give the latest ideas and technology a chance to be developed.



Thank you to Rosetrees Trust and to all our Ambassadors for supporting this project.

To read more about our Innovation Fund go to nationalbrainappeal.org/innovation



Neurology Empowering epilepsy patients

In the UK, more than 600,000 people have epilepsy. This is a long-term condition which accounts for over 1,000 premature deaths per year and costs the NHS £1.5billion annually. Both these figures could be significantly reduced by enabling people with long-term conditions to manage their health on a daily basis.

The Epilepsy Service at Queen Square has established a senior role for a clinical nurse specialist to lead and implement a programme of 'patient activation'. Patient activation means engaging patients with the skills and confidence to manage their own health and care. Research shows that patients who are more engaged are happier with their care and have all-round better health outcomes, as well as decreasing the cost to the NHS.

The newly appointed Senior CNS, Sasha Monaghan, will lead this programme. She says, "I will be developing ways to engage patients, so they can start to self-manage their condition more. This will be carried out in a number of ways: digital and online reporting and access to their own medical

records; education about epilepsy at the right level; building strong one-to-one in-person relationships with our patients and ensuring continuity of care – which is something we strive hard for at Queen Square already. I'm expecting that we will see an improvement in people's long-term health and also that they'll be even happier with the service we provide."

Senior clinical nurse specialist, Sasha Monaghan



The National Brain Appeal is providing £100,000 to trial this new role for 18 months. Following completion of the programme, if there is an improvement in outcomes, there will be an application to the NHS for ongoing funding and the learnings from this initiative will be shared so that people with epilepsy everywhere can benefit.

Neurology MRIs to expand multiple sclerosis knowledge

We have awarded £40,000 for a clinical study to determine the importance of peripheral nerve damage in multiple sclerosis using magnetic resonance imaging (MRI).

Multiple sclerosis is the most common disabling disease of the central nervous system in young people. While the disease is thought to be confined to the central nervous system (i.e. brain and spinal cord), biopsy and post mortem studies have found that the peripheral nervous system (PNS) is also involved.



Senior Research Associate and project lead, Dr Marios Yiannakas says, "Evidence from neuropathology has demonstrated that the peripheral nerves can also be affected in multiple sclerosis.

"These are nerves in the spinal cord and extend to the upper and lower limbs. We know very little about the relative contribution of this damage to the observed clinical symptoms. This is because these nerves are not routinely examined objectively, for example, using magnetic resonance imaging. What is exciting about this project is that we will be able to translate some of our most advanced imaging methods to the peripheral nerves to

address this gap in knowledge, potentially leading to tailored treatments in the future"

A minimum of 25 healthy volunteers and 25 patients with a diagnosis of multiple sclerosis will be recruited and clinically assessed.

Quantitative MRI results will be key to this project – this is when an MRI obtains numerical measurements during a scan as well as the more usual imagery. This can potentially offer greater accuracy, repeatability and speed of results.

The results will then be presented at relevant medical conferences and will be prepared for publication in medical journals.

Radio 4 Appeal success!

In August, our first ever BBC Radio 4 Charity Appeal was aired, raising awareness and vital funds for the Rare Dementia Support (RDS) service.

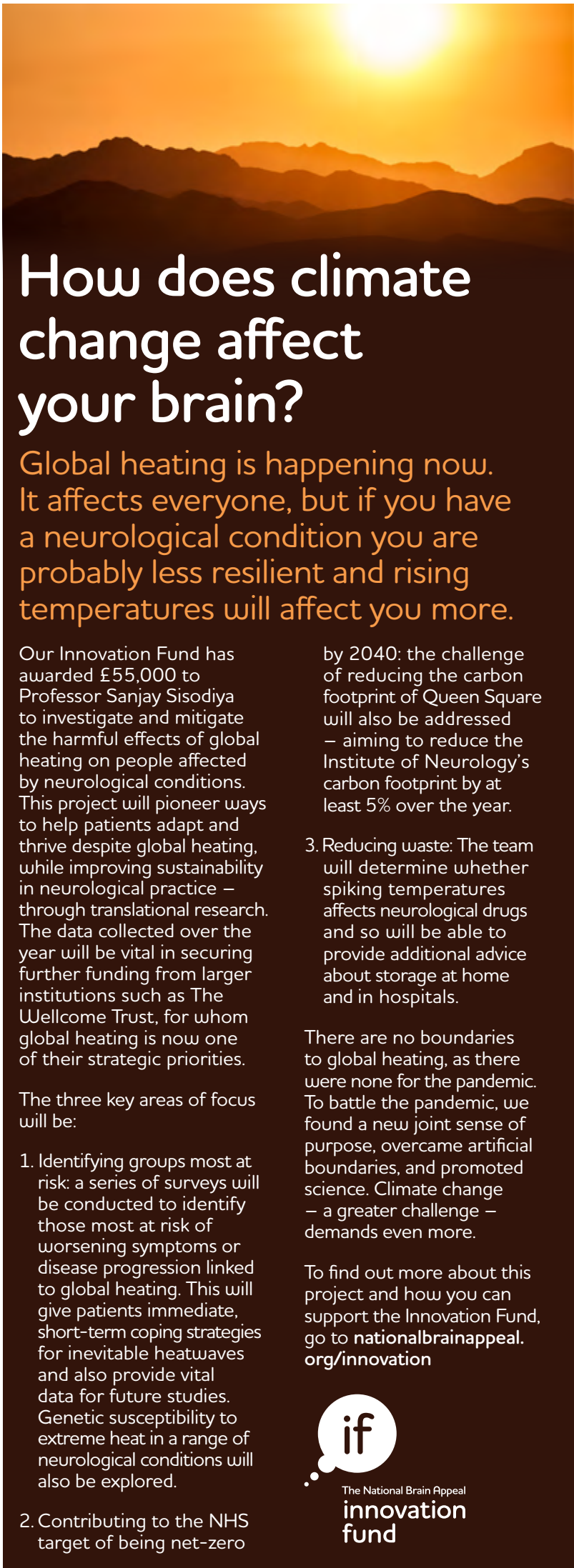
We asked RDS member Sophie Leggett (below) to front our appeal and share her story about facing dementia. Although she is only 45, Sophie recently discovered she carries a gene that causes Familial Alzheimer's Disease and she will develop early-onset dementia – probably in the next few years.



In the radio appeal Sophie revealed how she went through denial, diagnosis and then faced the future – which she now feels she is better equipped to handle – after receiving specialist advice and support from RDS.

She's now planning a lengthy road trip around the UK and Europe in a converted American school bus, called Barbara, the Good Life Bus! Sophie wants to have as many adventures as possible before her life changes.

We're delighted to announce that the appeal has so far raised just shy of £20,000! If you would like to listen to Sophie's very personal appeal, please visit nationalbrainappeal.org/r4 where you can also make a donation to help tip us over the £20k mark!



How does climate change affect your brain?

Global heating is happening now. It affects everyone, but if you have a neurological condition you are probably less resilient and rising temperatures will affect you more.


Our Innovation Fund has awarded £55,000 to Professor Sanjay Sisodiya to investigate and mitigate the harmful effects of global heating on people affected by neurological conditions. This project will pioneer ways to help patients adapt and thrive despite global heating, while improving sustainability in neurological practice – through translational research. The data collected over the year will be vital in securing further funding from larger institutions such as The Wellcome Trust, for whom global heating is now one of their strategic priorities.

The three key areas of focus will be:


1. Identifying groups most at risk: a series of surveys will be conducted to identify those most at risk of worsening symptoms or disease progression linked to global heating. This will give patients immediate, short-term coping strategies for inevitable heatwaves and also provide vital data for future studies. Genetic susceptibility to extreme heat in a range of neurological conditions will also be explored.
2. Contributing to the NHS target of being net-zero by 2040: the challenge of reducing the carbon footprint of Queen Square will also be addressed – aiming to reduce the Institute of Neurology's carbon footprint by at least 5% over the year.
3. Reducing waste: The team will determine whether spiking temperatures affects neurological drugs and so will be able to provide additional advice about storage at home and in hospitals.

There are no boundaries to global heating, as there were none for the pandemic. To battle the pandemic, we found a new joint sense of purpose, overcame artificial boundaries, and promoted science. Climate change – a greater challenge – demands even more.

To find out more about this project and how you can support the Innovation Fund, go to nationalbrainappeal.org/innovation



The National Brain Appeal
innovation fund



Unsung heroes of The National Hospital

We catch up with Rob Heggie, Head of Biomedical Engineering

What do you do in the hospital and how many years have you been at Queen Square?

I joined UCLH in 2007 and moved to Queen Square in 2010. I am Head of the Biomedical Engineering department. We manage and maintain the medical equipment at Queen Square. This ranges from small devices such as thermometers up to complex patient monitoring systems and anaesthetic machines.

Can you give an outline of your day-to-day job?

My main role is managing the Biomedical Engineering team who are the real 'unsung heroes'. I ensure that the repair records are kept up to date and investigate equipment failures. Since the start of the pandemic I've been busy trying to obtain sufficient extra equipment to cope with increasing patient numbers. This has involved working more closely with colleagues in neighbouring hospitals to share best practice and even equipment. Occasionally, I get to service or repair a piece of equipment – a task which I still enjoy.

Is the majority of your work based in the workshop or do you go out and about to fix items too?

We try to repair simple faults in the clinical area. This means equipment stays in use and patient care is not compromised. It's important for the team to visit clinical areas. It allows

us to help staff with any issues and we can often pick up a problem before the equipment breaks down. Equipment with complex faults will come into the workshop. The latest equipment is often connected to the IT network which enables us to monitor its status remotely. We can often spot problems before they happen.

How many of you are in the team and what kind of different skills do they bring to their roles?

There are eight members of the team. All are highly skilled engineers and technologists. Other skills are also important: kindness, tact, and diplomacy, plus the ability to teach clinical staff how to use the equipment.

What do you enjoy most about your role?

Working with clinical teams before we purchase any new medical equipment to check that it's going to perform in the way that they want it to. Meeting clinical need while also being easy to maintain, reliable and best value are all crucial factors. My aim is to ensure the team can keep the equipment at Queen Square well maintained and safe for our patients.

Are there any bad bits?!

In any job there can be a bad day, but I can honestly say that the hospital is a wonderful place, and it's a privilege to work with a great team and be part of the 'Queen Square family'.

Volunteers needed!

The National Hospital has an army of cheery volunteers who generously give up their time to help support hospital staff and patients – but they would love more!

Volunteers can perform a range of jobs including admin tasks, patient signposting, shopping for patients and delivering magazines and newspapers to the wards.

Marion is just one of these volunteers who are based at The National Hospital. She says, "My introduction to The National Hospital was in an ambulance! I was a patient for a month and went on to make a good recovery. I'm so grateful to the wonderful staff for this. Once I retired, I decided to support The National Hospital and joined

as a Welcoming and Guiding Volunteer at the reception.

"In this role, I love being able to help people in very



Marion

ordinary ways – reassuring them that they're in the right place and guiding them through what can feel like a complicated and confusing building. I'd encourage people to look at the opportunity of volunteering. There are lots of roles and you're bound to find something that suits you. It's a lovely team of volunteers too!"

If you'd like to join The National Hospital Volunteer Team, you'd need to commit to a minimum of three hours per week for at least 12 months.

You can apply at uclh.nhs.uk/work-with-us/volunteering



Christmas help

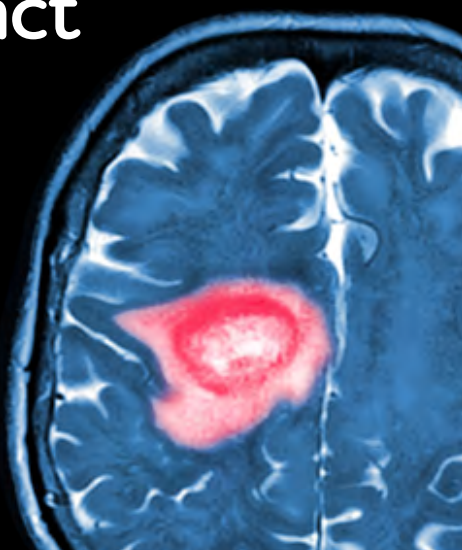
We're looking for people to give us a helping hand over the next few months to dispatch our Christmas merchandise orders. Think you might be able to spare 2-3 hours once or twice a week? Please get in touch by emailing lisa.finch5@nhs.net

The money you donate makes an immediate impact at The National Hospital. Read the latest developments and news from Queen Square



Brain cancer care: our impact

The National Brain Appeal is proud of its impact over the last ten years and more.



Since 2011, we have provided:

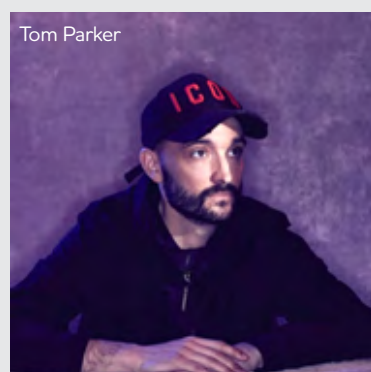
- £1million initial funding to establish the specialist brain cancer team and the Brain Tumour Unit. This funded doctors, nurses and researchers to enhance patient experience and develop research.
- £1.5million to fully fund the dedicated ward for brain tumour patients – the Molly Lane Fox Unit – as well as the UK's first interventional MRI scanner (to advance brain cancer surgery).
- £295,000 towards the immunotherapy trial led by Dr Paul Mulholland. This has been the most significant brain cancer clinical trial in decades with 119 patients recruited across seven sites. Dr Mulholland hopes to start follow-up brain cancer clinical trials later this year (see *Star Support*, right).
- £185,000 towards three research projects to develop new surgical instruments and techniques; to determine brain tumour boundaries; and, to develop image-guided adaptive radiotherapy – all with the goal of reducing the size of tumour remaining after treatment, without inflicting other damage.

Together, these developments have helped establish The National Hospital as a world-leading centre for brain cancer.

If you would like to be part of our commitment to continue raising funds to support new treatments for and research into brain cancers, please make a donation at nationalbrainappeal.org/brain-cancer

Star support

Our Brain Cancer Research Appeal has recently had a large boost thanks to Tom Parker (from band The Wanted). Last year he was diagnosed with an aggressive form of brain cancer – glioblastoma – and has since thrown himself into raising awareness for this hugely underfunded area.



“I was shocked to discover that only 1% of the annual research budget for cancer is devoted to brain tumour research.”

Tom Parker, The Wanted

In September 2021 he organised a fundraising concert called 'Inside My Head' to raise money for brain cancer research. He says, “My world was turned upside down by my diagnosis. I was absolutely shocked to discover that only 1% of the annual research budget for cancer is devoted to brain tumour research. That's why I am supporting The National Brain Appeal. I want to use my voice and platform to do something about it and help in any small way I can. Music is my life so a concert to raise much-needed funds seemed like the perfect idea.” The night, organised by SU2C, featured a stellar line up including his reformed group, The Wanted, Liam Payne, KSI, Sigrid, Becky Hill, McFly and Ed Sheeran. Proceeds will help to support the follow-on trials for those diagnosed with glioblastoma.

Aphasia therapy to restart

The Intensive Comprehensive Aphasia Programme (ICAP) is a programme which was created to help improve language function in adults with aphasia following acquired brain damage, for example as a result of a stroke, a traumatic brain injury or a brain tumour.

As part of The National Hospital's response to Covid, the ICAP team had to be redeployed and the service was paused. Nonetheless, 47 patients were treated in the first year and the programme is scheduled to restart later this year. When the service restarts, the model will move to four days per week over four weeks – remaining high-dose but less fatiguing for patients and their families.

The programme is led by Professor Jennifer Crinion and Professor Alexander Leff. They are now working with The National Hospital management team to apply for specialised NHS commissioning for the programme.

We are raising £600,000 to fully fund the pilot programme and have raised more than half of the funds needed. To support this vital work, please visit nationalbrainappeal.org/what-we-do/current-appeals/aphasia

Actors flock to Queen Square

Recently, Queen Square – and particularly the Rare Dementia Support (RDS) team – has

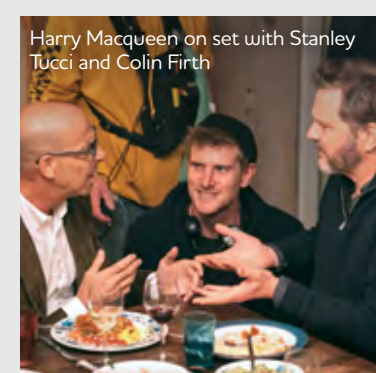
become a magnet for TV and film production companies as well as actors seeking advice about unusual types of dementia while researching roles. UCL's Dementia Research Centre (DRC) is a world-leading hub of expertise for atypical types of dementia. The National Brain Appeal provides funding of £350,000 a year to the support service.

One of these projects is the film, *Supernova*, which features Colin Firth and Stanley Tucci, who plays his partner living with early-onset dementia. This was released over the summer in cinemas to great acclaim. Director Harry Macqueen talked directly to Rare Dementia Support (RDS) group members. He says, “*Supernova* is the result of a lengthy and immersive research process. I worked closely with the UK's leading dementia specialists at UCL and The Wellcome Trust and collaborated with many people affected by the condition.”

In addition – *Help* – a Channel 4 drama, addressed the issue of early-onset dementia in a care home setting at the height of the pandemic. Actors Stephen Graham and Jodie Comer both received advice and guidance from the Direct Support Team at RDS when researching their roles. Stephen has since been helping us to raise awareness for the Rare Dementia Support Centre Appeal. He says, “When researching my role, I was fortunate enough to spend time with the people at Rare Dementia Support. I could really see how frustrating it was. I shed a few tears if I'm honest, with the lovely people that I met, and I carried them with me through the filming process.”

Finally, *Second Spring* was released in cinemas recently and follows the story of a woman (actor Cathy Naden) who is diagnosed with Frontotemporal dementia (FTD). Director Andy Kelleher spent time with Professor Jon Rohrer from the DRC – a leading expert in FTD – to ensure the challenging and unusual symptoms of FTD were accurately portrayed.

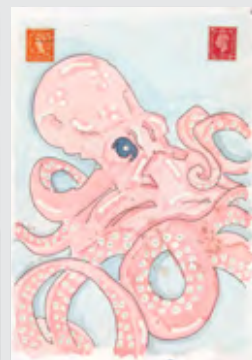
It's real testament to the knowledge and expertise of the RDS Team that their advice is so sought-after!



Harry Macqueen on set with Stanley Tucci and Colin Firth

We are offering a mix of virtual and in-person events –please join us!

EVENTS



supported us this year by getting creative.

We've lots of celebrities and artists taking part, including Chris Riddell, Laurie Chetwood, Andrew Grant, Chantal Joffe, Bethan Woollvin, Tim Hoggood, Luke Morgan, Morag and Ishbel Myerscough, Tom Hammick, Mark Entwisle, Andrew Marr and Harry Hill!

New for this year, we're running online art workshops hosted by artists supporting A Letter in Mind. If you have registered to take part in ALIM, or have entered an artwork, we'll contact you with details! If not, but you'd like to hear more about the workshops, email us at letterinmind@nationalbrainappeal.org to register your interest. Keep an eye on our website and social media for announcements.

Sales will once again take place online with the gallery available to preview from 2 November. This gives you a chance to browse before buying opens at 11am on 4 November at aletterinmind.org



Get ready to click and buy, because A Letter in Mind is almost here!

Our postbags have been filled with some stunning pieces of envelope artwork. Thank you to everyone who has

One artist's story

The last two years have been very dramatic for Oliver Roberts.

Oliver is a production designer and art director, known for working on blockbuster films, including Harry Potter and Star Wars. At the start of 2019 he'd been feeling unwell, with occasional headaches and vomiting. While working on the film 1917, set in a quarry, he struggled to put on his wellies and waterproofs. He says, "I had to be up and out by 6am, but there were days where I literally couldn't get in the shower."

Oliver's wife Eliya knew something was wrong and suspected it might be a brain tumour. Their GP, however, thought that it might be a reaction to certain foods and advised him to keep a food diary.

On a family holiday in the south of France, Oliver's symptoms worsened. Eliya took him to the nearest hospital, in Carcassonne, where they



carried out CT and MRI scans of his brain, discovering a massive tumour. He was unable to fly due to the cabin pressure, so his family booked a private ambulance to take him the 20-hour journey back to London. After being assessed in A&E at UCLH, Oliver was transferred to The National Hospital. He was diagnosed with a meningioma brain tumour with a rare TERT mutation. In April 2019, consultant neurosurgeon Andrew McEvoy and team operated to remove as much of the tumour as they could, but it was the size of a grapefruit – and the surgery took 11 hours. After some time on the high dependency unit, Oliver was moved to The Molly Lane Fox Unit, the specialist brain tumour ward that The National Brain Appeal funded.

Oliver says, "I had a real empathy with the other people on the Molly Lane Fox Unit. I remember a man in the next bed encouraging me to be strong when I was having a difficult time."

In December that year, Oliver had a violent seizure that caused him to fall and dislocate his shoulder. An MRI scan showed that his tumour had come back and was already almost as big as before. In early 2020 he had further surgery, followed by radiotherapy and then gamma knife treatment in July this year. Oliver continues to be monitored by the team at Queen Square.

Oliver and his family are very grateful for the specialist care that he has received. His brother Tom aims to raise £5,000 by running the 1,240 kilometre distance that Oliver's ambulance took to repatriate him for the urgent treatment that he needed. Oliver is taking part in this year's A Letter in Mind with an anonymous envelope artwork and has also created an advent calendar of his drawings, inspired by Queen Square! This beautiful advent calendar is available from our online shop at nationalbrainappeal/shop for just £10!



Run the 2022 London Marathon!

The London Marathon is one of the greatest marathons in the world, so don't miss out on your chance to take part. Next year's London Marathon will take place on Sunday 2 October 2022 and will be a real celebration as we see thousands of runners taking on the 26.2 miles across London, many running for amazing causes.

Our ballot runners are asked to commit to raising £2,000 and we will provide you with

fundraising support along the way and access to the We Run app to help you train and stay injury free. To apply for a place, visit nationalbrainappeal.org/event/londonmarathon If you have any questions, email alexis.gebbie@nhs.net

It's not too late to support Queen Square neurosurgeon Neil Kitchen who ran this year's London Marathon with his son, Jim. Go to justgiving.com/fundraising/neilkitchen21 to donate!



Christmas is coming!

We are delighted to announce the return of the Christmas Concert on Thursday 16 December at St George's Church*, Queen Square.

Doors will open at 6.30pm with a welcoming glass of mulled wine, and the concert will start at 7.15pm. We will be joined by special guests, including readings from actors Jim Carter (best known for his role in *Downton Abbey*) and *Bridgerton*'s Bessie Carter. There will also be uplifting music thanks to the The Julius Singers and former neurosurgeon Mick Powell on saxophone accompanied by neurologist Nick Losseff on piano. Please keep an eye on our website for further performer announcements.

Tickets are £25 and can be purchased online at nationalbrainappeal.org/event/christmas-carol-concert or by using the form on the Christmas leaflet enclosed. If you are NHS staff and would like to attend, please contact events@nationalbrainappeal.org for discounted tickets.

*New Covid restrictions permitting.

Thank you to the event sponsor, Danny Sullivan Group for supporting this event and helping to make it possible.



Time to reflect

We know how important it is to celebrate the lives of our loved ones.

November is traditionally the month of remembrance so we have created a tribute page for you to share your special memories of a loved one. Simply go to bit.ly/celebrate-a-life



To find out more about any of our events, please go to nationalbrainappeal.org/events

Your donations and support have been funding major new developments, patient care and research at The National Hospital for the last 35+ years

SUPPORT

Dates for your diary

November

4: A Letter in Mind

December

16: Christmas Carol Concert

January 2022

1 (ongoing): Neural Pathways
1 (ongoing): BrainWave

April 2022

3: London Landmarks Half Marathon

October 2022

2: TCS London Marathon



Making a difference for the future

The last 18 months have prompted many of us to reflect on the things that really matter – family, friends and the causes close to our hearts.

We've also been reminded of the value of planning for the future, to help look after the things we care about most. Did you know The National Brain Appeal offers reduced rate Will-writing services, thanks to our partners, Bequeathed and The Goodwill Partnership? This means it's easier than ever to pass on something wonderful. After taking care of your family and friends, even a small amount left in a Will can make a huge impact to our work.

Joan Grieve is a consultant neurosurgeon at The National Hospital and a Trustee at The National Brain Appeal. She says, "I see first-hand the impact that gifts in Wills can have. From ground-breaking research to innovative new treatments, much of what we are able to do now is due to legacies made in the past. Your generosity can have a huge impact on patients and their families for generations to come. Will you consider investing in the future by remembering The National Brain Appeal in your Will?"

To find out how to make your free Will visit nationalbrainappeal.org/legacy

bequeathed
free wills, valuable advice

the Goodwill Partnership

Making a donation

To support the work of The National Brain Appeal, please complete this form.

I enclose a donation of (please tick appropriate box)

☐ £20 ☐ £30 ☐ £50 ☐ £100 ☐ other £ _____

I would like my donation to go towards (tick appropriate box)

☐ General Fund ☐ Neurodegeneration ☐ Neurology
☐ Queen Square ☐ Technology & Innovation
☐ Neurosurgery ☐ Education & Staff Development

giftaid it

You can make your donations worth **25% more** (that's £5 for every £20 donation!) to people with neurological conditions* – simply tick, sign and date the declaration:

☐ Yes, I want to Gift Aid my donation and any donations I make in the future or have made in the past four years to The National Brain Appeal

Signature _____ Date _____

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Please notify the charity if you:
– want to cancel this declaration.
– change your name or home address.
– no longer pay sufficient tax on your income and/or capital gains.

*Please note you must fill in the name and address details, right for your Gift Aid declaration to be valid.

Regular Giving



Could you spare a few pounds each month to help us fund advances in neurology and neurosurgery? Regular Giving is a simple and effective way to make an immediate impact. Funds raised this way support our major projects but also enable us to respond quickly to urgent or new requests.

To make a regular donation by Direct Debit please call the office on 020 3448 4724 or visit nationalbrainappeal.org/donate

☐ Please post me further information about making a regular donation by Direct Debit

Contact and payment details

Title _____

Forename _____

Surname _____

Address _____

Postcode _____

Telephone _____

Email _____

Payment by cheque

I enclose a cheque for £ _____ made payable to The National Brain Appeal.

Payment by credit or debit card

Name on card _____

Card number

Expiry date on card /

CVV code (last 3 digits)

Total amount £ _____ Signature _____

Thank you for your support.

☐ We would like to send you a thank you but if you'd prefer not to receive one, please tick here

☐ I would like to receive email updates about the latest clinical breakthroughs, fundraising activities, and events.

☐ Please send me information on leaving a gift in my Will

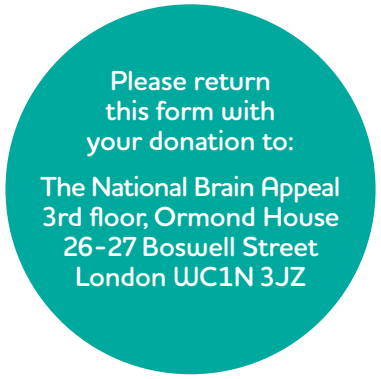
Privacy Policy

The National Brain Appeal is committed to protecting your privacy. We use personal data to communicate with our supporters – like you – keeping you up-to-date with our news, campaigns and fundraising information.

You can unsubscribe by calling the office on 020 3448 4724 or emailing info@nationalbrainappeal.org

The National Brain Appeal will never sell or swap your personal data and will only share it, when necessary, with organisations that work with us to manage our data processing and mailings – and where your privacy and security is guaranteed.

You can read our full privacy policy at: nationalbrainappeal.org/privacy-cookies-policy



Thank you to everyone who has done so much over the past months to raise vital funds for The National Brain Appeal

THANKS



Anil Tailor

Lockdown mop chop

Thank you to Isha Tailor who managed to raise £1,950 after convincing her dad, Anil, to have his lockdown mop chopped! After surpassing the original target of £450, Anil also agreed to shave his head and beard if Isha raised £1,500, which she did! Congrats to Anil for braving the shave and to Isha for your fabulous fundraising.



Tom and Ed

Ultra heroes

On 29 May, Tom Morison and Ed Speleers embarked on an epic 200km ultra marathon along the South West Coastal Path, raising a whopping £28,700 towards our Rare Dementia Support Centre Appeal. Tom's dad was diagnosed with a form of rare dementia and Tom and Ed did an excellent job of raising awareness and vital funds so that other people affected can also be supported. Tom says, "It was one of the most challenging, emotional, and life-affirming moments of my life. I know that my Dad was excited and proud of our run – he was so eager to be at the finish to share the moment with us." Well done Tom and Ed, this is an incredible amount!



Abbi and Richard Blakey

Walking wonders

Thank you to Abbi and Richard Blakey, and James Pattison for taking part in the

London 2 Brighton Challenge, trekking 100km and raising an impressive total of £5,600. Richard recently became a trustee of The National Brain Appeal, and did an incredible job of showing his dedication to the charity, saying, "We are delighted with how much we've raised and that makes the achey legs worth it!"

Patrice Saiman's memoir



Fundraising memoir

Patrice Saiman recently published a memoir, *The Missing Baluster*, which he celebrated with an online launch with family and friends. Patrice very kindly asked for donations to be made to The National Brain Appeal as a thank you for the care he received following two brain haemorrhages and raised a fantastic £1,330! Patrice's book documents his fascinating life and is available at troubador.co.uk/bookshop/biography/the-missing-baluster-hb/

Hadrian's Wall hike

Congratulations to Helen Drew, who embarked on an 84-mile hike along Hadrian's Wall, raising an incredible £4,300. Helen says, "In June 2014, I successfully underwent brain surgery at The National Hospital. After receiving excellent care and treatment, I wanted to help and improve the lives of others with a neurological condition". Helen, your fundraising will make a huge difference!



Author support

We are extremely grateful to Rare Dementia Support (RDS) member Christine Reddall, author of *Anna and the Beast* who has donated profits from her book sales and held virtual market stalls to fundraise on top! She has documented her account of the five-year battle caring for her daughter with Behavioural Variant Frontotemporal

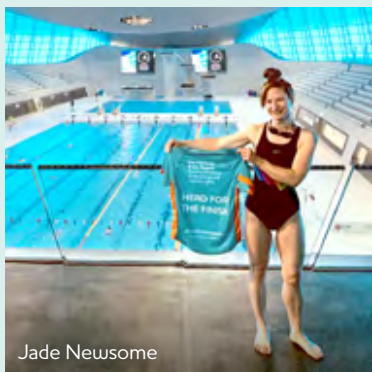
dementia. Buy the book from nationalbrainappeal.org/shop at a discounted price. Christine has raised £2,300 for RDS. Thank you so much.



Christine Reddall

Summer of swimmers

Thank you to Jade Newsome and Tanya Spensley who took part in our BrainWave challenge, swimming a total of 70km and raising £3,500 collectively. Both Jade and Tanya were treated at The National Hospital and wanted to give something back. Thank you also to Lisa Peake and team, who swam the English Channel in July, raising an incredible £4,000 and to Jo Swift who swam 8.5km of the River Thames raising £1,400! We are blown away by all your efforts. Want to take on BrainWave? Visit nationalbrainappeal.org/event/brainwave



Jade Newsome

Skydiving for dementia

After Sue Mabbutt was diagnosed with PCA, a rare form of dementia, she decided she wanted to take on a thrilling challenge to help others affected by rare dementias. Sue completed her skydive in July, raising a wonderful £3,760 and was delighted to take on the challenge after an 18-month delay due to Covid-19 restrictions. Well done Sue!



Sue Mabbutt



Sam McMeekin

Triathlon triumph

Energetic duo Sam McMeekin and Sarah McMeekin have been superstars this summer. Sam completed two triathlons while Sarah ran a total of 100 miles. They raised £6,320 and unlocked a further £5,000 of matched funding from an anonymous donor, towards our Rare Dementia Support Centre appeal! Sam and Sarah took on these challenges after their dad was diagnosed with a rare form of dementia, Primary Progressive Aphasia. Sam says, "I'm so grateful to everyone that's donated to a charity that has given our family a lot of information regarding this rare illness."

Family challenge

Thank you to Simon Horne and family for walking an epic 100km along the South Downs Way to raise money for our Brain Cancer Research Appeal, in memory of mum and nana, Lydia. The trek took just under 26 hours and the family have raised an unbelievable £25,000 which was split between The National Brain Appeal and Brain Tumour Research. Simon says, "The care and attention Mum received at Queen Square was simply amazing. I know Mum would have been proud and staggered at the amount of money we've raised."



Simon and his family

Regular giving

Every day, thousands of people in the UK are diagnosed with a neurological condition.

Each one of them is someone's mother, father, son or daughter. We're proud to support two world-leading centres of excellence: The National Hospital and the UCL Queen Square

Institute of Neurology. Their research and the resulting treatments for neurological and neuromuscular conditions is vital.

Will you be part of the search to find new treatments for these conditions by pledging a regular gift today? Funds raised this way support our major projects but also allow us to respond quickly to urgent need.

To make a regular donation visit nationalbrainappeal.org/donate or call the office on 020 3448 4724.

Contact us

The National Brain Appeal
Funding advances in neurology and neurosurgery

NEURO
MUSCULAR
STROKE
EPILEPSY
DEMENTIA
PARKINSON
MIGRAINE
SPINAL
MULTIPLE
SCLEROSIS

There is now a small team in the office most days but staff are still mainly working from home. We are all contactable on email and the address for any general enquiries is info@nationalbrainappeal.org

We'll do our best to respond to you as quickly as we can but it may take longer to respond to postal or telephone enquiries. Please stay in touch with us on our social channels (see right).

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