

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

Newsletter
Number 58
Spring/Summer
2021

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

Springtime
challenges

Long Covid
clinic opens

Mitochondrial
research



THE NATIONAL BRAIN APPEAL

And now on Radio 4...

We're excited to announce that The National Brain Appeal has been successful in a bid for a Radio 4 Charity Appeal for our Rare Dementia Support (RDS) Fund this autumn.

This appeal will be heard nationwide and help to raise the profile of the service, the support it offers to those living with a rare form of dementia – and its vital need for funding.



Supporter and RDS member Sophie Leggett has kindly agreed to share her story about the huge impact that the support group and service has made to her life.

Please sign up to our RDS e-newsletter (four issues a year) at nationalbrainappeal.org/RDS so we can keep you updated and let you know when to tune in!

Letter from our Chief Executive



Like most charities, this time a year ago we had no idea if we would be able to deliver the funding needed for our essential projects or if we would have to make cuts in our activity and our grants.

Thanks to our amazing supporters, not only have we been able to continue in line with our plans, with just a few projects being slightly delayed, most have managed to continue and we have actually funded a number of additional projects – from emergency Covid-related initiatives – to new research and clinical projects for various neurological conditions.

The staff team have shown incredible dedication, despite the difficulties of entirely changing how they work and in some cases, also suffering personal bereavements. It has been far from easy, but they have demonstrated immense commitment – not only ensuring that the show went on as much as possible, but that we introduced and tested all sorts of new ways of working.

Contact us

Due to the ongoing coronavirus situation, the charity team is still mostly working from home, with a limited number of staff in the office twice a week. 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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“Queen Square staff should be very proud”



Dr Chris Turner, Divisional Clinical Director for The National Hospital and Consultant Neurologist, shares his thoughts on the last few months.

It is often difficult to know when major events start and finish in life but for the second Covid surge in December 2020, the start was very clear.

There had been a few concerning phone calls in mid-December and snippets of data which raised eyebrows, but the spirit of a much-needed festive break for staff was in the air. On the

morning of 21 December 2020, our Covid landscape changed with a ferocity that no one fully predicted. For many staff, their much-deserved leave was so close and yet would have to wait for another year – cut short in a moment of realisation that the inevitable was happening.

I have personally never had to ask so many staff to do so many things, with so little notice. When doctors become healthcare assistants and fill shelves with endless flows of life-supporting consumables, when nurses care for many times more lives than is familiar, when therapists provide news for separated families who hang onto every word of hope for the lives of loved ones, and managers, who have never stepped into the frenzy of a busy Intensive Care Unit, become part of a life-saving “proning” team, then, and only then, do you realise the enormity and power of the human spirit. We all owe a debt of gratitude to those staff who played their part.

Queen Square should be proud of the role it played in the wider sector in taking Covid and neuroscience patients from a broader geographical area to support local ITU responses. Many of our ITU patients did not

start their patient journey local to UCLH.

The future still has an air of financial, professional and personal uncertainty and we are supporting all the teams to return to pre-Covid activities as part of our recovery plans. As a Trust, we would like to maintain many of the positive developments that came out of our Covid response, including virtual access to clinics, as well as continuing to develop our acute neuroscience services at Queen Square. The Covid pandemic has also brought into sharper focus the physical and mental wellbeing of our staff. The quality of our clinical services is dependent on our teams being engaged, healthy and motivated.

Many thanks to all the supporters of The National Brain Appeal who made a difference with their generous donations. This enabled so many things for the Queen Square staff who were often working at their limit. Your contribution brought many smiles to many teams.

Let us now go forward and look to a brighter future where the lessons of the past year can lead to greater awareness and translation of the needs of all our patients and staff.

Our hugely successful fundraising art exhibition, A Letter in Mind, returns for the eighth year!

This year's theme is 'Making your Mark' and we're hoping for some powerful and creative responses from artists, illustrators and designers.

After a year in and out of lockdown, many of us have had time to reassess our place in society and in the world. We are looking to tentatively re-establish our relationship with everything around us, as well as adapting to how things – including ourselves – might have changed.

How do we make our mark in this different world? Do we want to continue life in the same way as before? Do we feel strongly about another role, cause or way of living? Is it back to the humdrum or can we influence, inspire and 'make our mark' in new and improved ways?

People have made marks to connect, tell stories and communicate since time began. Alongside the growth of the digital world, hand-made creations still have a strong and powerful ability to affect us in an increasingly 'hands off' virtual environment. All you need is a simple envelope as your starting point and the rest is up to you.

Previous artists include Grayson Perry, Chantal Joffe, Ishbel Myerscough, Morag Myerscough, Mark Dion, Gill Rocca, and Mark Entwisle; designer Zandra Rhodes; illustrators Chris Riddell, Tim Hopgood and Polly Dunbar;

architects Laurie Chetwood, Andrew Grant and Amin Taha; comedian and presenter Jo Brand; journalist and presenter Andrew Marr; actors Joanna David, Kevin Eldon, Sophie Thompson and Phyllida Law.

The deadline for entries is 16 July and artworks will be available to preview and buy online from 3 November. The artwork envelopes will all be priced at £85 and sold via our online gallery. As always, all proceeds from sales will support vital projects at Queen Square.

For all the information you need and to register to take part please visit aletterinmind.org

We can't wait to see how you'll be 'Making Your Mark' this year!



A LETTER IN MIND



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 Small ideas, big impact

Our Small Acorns Fund has enabled a further six projects in the last round of applications.

This has included funding a simulation mannequin for The Medical Intensive Care Unit (MITU). The unit provides a plasma exchange service to around 150 patients a year. These patients have Portacaths – permanent under-the-skin access ports. Learning to access and care for these devices requires ongoing training. This grant will enable the MITU team to purchase a mannequin with a variety of different intravenous lines and accessories to help educate staff to safely use and care for these ports – without posing any risk or discomfort to patients. Initially, 12 MITU nurses will be trained using the simulator but it will benefit the whole of the neurocritical care nursing team.

We also funded the development of a new support and information website for patients living with Cerebral Amyloid Angiopathy (CAA). This fairly common condition is caused by a build-up of a protein called amyloid beta within the walls of small blood vessels near the brain surface. In the Queen Square stroke service alone, more than 100 people with this form of brain haemorrhage are seen every year. The new website will enable and empower people to access information about prevention, diagnosis and support. The aim is to include surveys and questionnaires to help inform ongoing research and to encourage patients to help to design any future trials or studies, as well as aid service improvements.

To donate to Our Small Acorns Fund please go to nationalbrainappeal.org/small-acorns. Read about our crowdfunding campaign for Small Acorns on p4.



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



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



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



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



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



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



The entrance on Gray's Inn Road

Queen Square Building work begins on neuroscience centre

Groundwork and clearance of the site at Gray's Inn Road – a world-leading centre for neurological disease research – has started. The redevelopment of the site retains and reuses parts of the previous buildings that are of most historic interest and the remaining structures are in the process of being demolished, soon to be replaced. The build of the substructure is scheduled to start from mid-summer. It will be a sustainable build – aiming to reduce carbon emissions by 40% and producing low levels of landfill waste from the construction process.



The north side of the new building on Gray's Inn Road



Labs will share equipment, space and services to encourage collaboration and efficiency



New landscaped areas include a sensory garden, a courtyard and plenty of green space

The images shown are artist impressions of UCL's new neuroscience centre
All rights reserved by UCL

Neurodegeneration Mitochondrial research

We are delighted to have recently fully funded a biomedical translational scientist position. Dr Pdraig Flannery is now in post and working on a new collaborative Queen Square service to support patients affected by mitochondrial disorders.

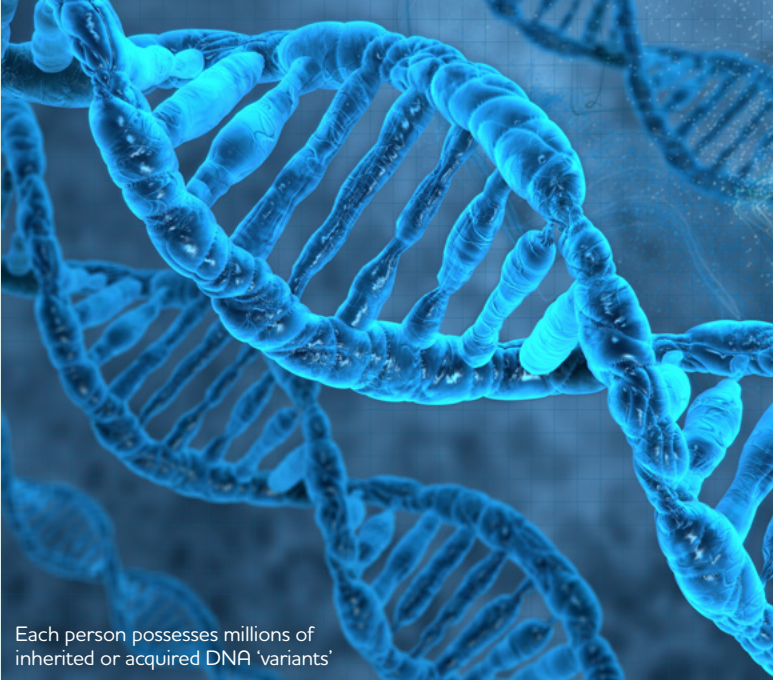
Sequencing the human genome was a scientific triumph of the early 21st century which gave a blueprint for exploring the basic unit of human inheritance – the gene. In 2012, the UK government led the way on an ambitious new enterprise to expand this technology and provide a new NHS medical service. This successful venture, known as the 100,000 Genome Project, provided advanced diagnosis for both cancer patients and those with rare inherited disorders. However, one of the major challenges still faced today is the diagnosis of patients where the underlying genetic cause is not obvious.

Each person possesses millions of inherited or acquired DNA changes or 'variants'. While some of these variants are well defined and can indicate disease inheritance, treatment and outcome, many people are left undiagnosed because they have variants of unknown significance (VUS). These VUS

lack sufficient clinical evidence to determine if they cause disease. This means many patients and families feel in limbo – without a diagnosis or access to appropriate care.

"This problem is particularly acute in patients with mitochondrial disease," explains Professor Simon Heales, one of the clinical leads. "This is because the disease is caused by mutations in a large number of genes across two different genomes. To bridge this gap, and thanks to this research funding, we can now begin to plan a new aspect to our service and provide bespoke diagnostic functional tests. These will give insights into the effect of DNA variants on mitochondrial function and their impact on patient health."

He continues, "This service – which I'm leading, along with Dr Robert Pitceathly, Dr James Polke, Dr Robyn Labrum and Dr Pdraig Flannery – will bring together both clinical genetics and functional biochemistry. For patients, this will mean that we will be in a much stronger position to provide a definitive diagnosis. Furthermore, by adopting this combined approach, we will be able to develop better targeted treatments."



Each person possesses millions of inherited or acquired DNA 'variants'

New faces

We are delighted to welcome four new members to our Board of Trustees.

Richard Blakey has extensive experience of working within and with charities – both as a senior finance employee but also as Trustee. **James Knight** runs his own communications agency having worked in the sector for many years and has a close personal connection to Queen Square. **Jules Foster** has wide-ranging experience within the charity sector, fundraising for the Tate, Oxford University and now for the International Red Cross Committee. **Suzanne Millar** has a wealth of strategic fundraising experience and

worked for Cancer Research UK for several years before moving to the Crisis Christmas Campaign at the end of last year. Together they will help drive our strategy in particular around digital engagement, partnerships and finance. We look forward to working with them all.

We'd also like to say a fond farewell to long-standing Trustee **Herchel Maclear-Jordan** who stepped down from the Board in October 2020. Hercchel brought a huge amount of commitment and energy to our fundraising activities helping to raise large sums for us, especially at our events. She was also a dab hand at persuading her friends and family to donate their valuable time, prizes and funds to support our work! Thank you Hercchel – you will be missed.

Feed our fund!

This summer we will be launching a month-long crowdfunding campaign to raise money for our Small Acorns Fund.

Feed our Fund is based around the need to keep our Small Acorns Fund growing strong. It's been so successful that we



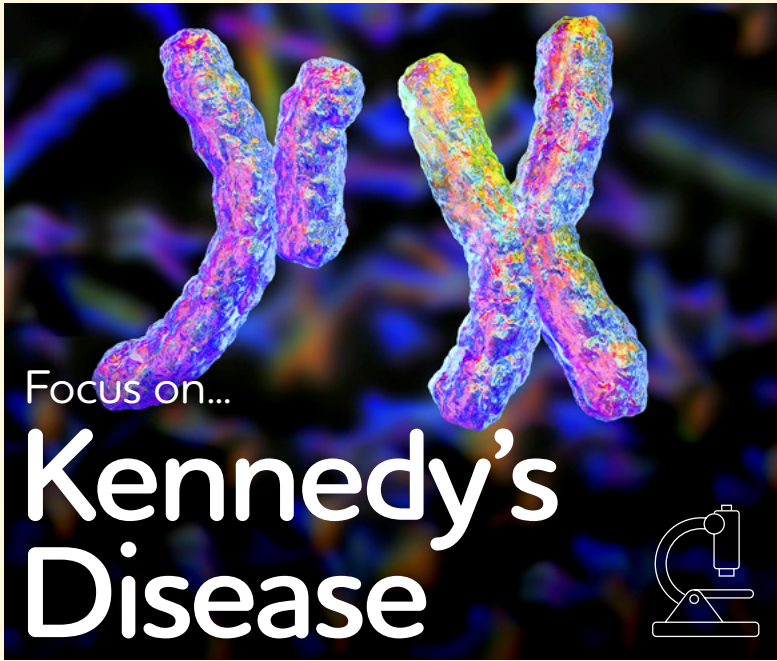
currently only have enough in the pot to fund the next round of projects – and we need new donations so that we can continue to support the innovative ideas identified by staff at Queen Square.

Chefs and restaurants around the country were invited to work with us on this initiative and there are a range of Brain Food products and experiences

that you'll get as a reward for donating! If you donate to Feed our Fund, you could get:

- ★ Brain Food e-book, which contains recipes from top chefs such as Thomasina Miers
- ★ Brain Food tea towel
- ★ Brain Food tote bag
- ★ Raffle ticket entry with the chance to win a number of prizes, including a Dishoom Meal and a chef cook-along!

For more details keep an eye on our website, social channels and your inbox for how you can show your support!



Hundreds of neurological conditions are treated at Queen Square. This issue, we focus on Kennedy's Disease.

What is it?

Kennedy's disease (KD), or X-linked Motor Neuron Disease, is a rare, inherited neuromuscular disorder also known as X-linked spinal and bulbar atrophy. It is an adult onset, progressive disorder, which only affects males and sees the degeneration of lower motor neurons within the spinal cord and brain stem. This causes weakening and wasting of the muscles, especially in the arms and legs.

KD is caused by a genetic mutation of a specific gene

on the X (female) chromosome. It's estimated that 1 in 40,000 people have this genetic defect and because it is relatively rare, Kennedy's Disease is often initially misdiagnosed or goes undiagnosed for years. There is no cure for Kennedy's Disease at present.

Symptoms

The many symptoms of Kennedy's Disease generally first appear between the ages of 30 to 50 years old. These can start with small trips and falls, painful cramping and uncontrollable muscle spasms. How the disease affects a person over time varies. In some it only affects mobility in later life, but in others it can attack many muscles

often making it difficult to even swallow liquids or confining them to a wheelchair.

The treatment

A diagnosis is normally given by a neurologist after genetic testing to establish if KD is present. While there are currently no curative treatments available, peoples' symptoms can be managed with different techniques and medication to maintain their strength and mobility. It's a disease that requires a multi-disciplinary approach with input from physiotherapists, speech and language therapists and respiratory doctors.

Research

A number of novel treatments are being trialled globally for Kennedy's Disease. At present, studies are being done with anti-androgen agents such as Leuprorelin to see if these may improve symptoms. There are also studies looking at the effect of salbutamol (commonly used for asthma) on improving muscle symptoms which are showing promising signs. Queen Square is currently involved in exciting research to create a new targeted gene therapy to reverse the effects of the genetic mutation in muscle to treat the disease. It is in the early stages but if successful it would make a huge difference to people.

Dr Jayaseelan*, consultant neurologist, says 'The Kennedy's Disease Clinic at The National Hospital is the only clinic dedicated to this disease in the UK. We see more than 80 patients a year and aim to give them access to specialist expertise and focus on finding effective treatments. Many of our patients are actively involved in our clinical trials to understand the disease better and test novel treatments that may improve symptoms and stop progression. The clinic has continued to run during the pandemic with video clinics allowing patients to still have access in the safest possible way.'

**Thanks to a very generous donor. The National Brain Appeal has funded Dr Dipa Jayaseelan's post for The Kennedy's Disease Clinic.*

A patient's perspective

'Throughout my 20s I got agonising cramps in both legs but thought nothing of it.

Then, in my early 30s, I noticed myself feeling less fit and stairs becoming tiresome. I worked on London Underground and one day, I went to pull myself up onto a train but I froze. Inside, I was straining with all my might to move, but nothing happened. After visiting my GP and having various local hospital referrals – first to

Boston Hospital and then to Queen's Medical Centre at Nottingham, I had extensive tests. A neurologist said I had a rare condition called Kennedy's Disease. I was his first ever case of KD and he couldn't give me a clear idea about disease progression. I felt like I'd been hit around the head with a baseball bat and knew my career was over on the railway.

Nowadays I'm hardly able to walk, so I use an electric wheelchair to get around. I have a Motability vehicle, a big van with rear lift, which allows me to transfer to the driver's chair internally. My wife is my carer – without her I would be lost.

Being seen at the KD Clinic at The National Hospital has been very helpful. It's meant I could be monitored and any issues quickly identified. If I'm having a problem, I contact the clinical nurse specialist, which gives peace of mind for me and my family. I have two children – my son is lucky enough to be KD free, but my daughter is a carrier. At least she's aware of the disease now and can do something about it, when she wants to start a family.

I don't think I'll see a cure in my lifetime, but now we have the technology with IVF to be able to implant non-KD affected embryos.'

Rick Webb, KD patient

people like Ron. We believe in investing in the very latest ideas in neurology to ensure that the best and newest techniques are available to patients.

Our dedicated Ambassadors for Innovation fully fund the Innovation Fund. Want to know more about becoming an Ambassador? Please email jane.ferguson9@nhs.net.



The Innovation Fund is funding Hani Marcus's breakthrough work to develop a 'smart instrument'. This will be smaller, cheaper, give 'wrist-like dexterity' and limit the forces exerted by surgeons to hugely improve this type of surgery for

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



Michael Rosen shares his support

More than 80 people affected by Long Covid have now been seen at the Covid Neurology Clinic – funded by The National Brain Appeal – since it opened in November 2020. We responded to urgent requests from doctors at the hospital faced with growing numbers of patients with neurological complications after contracting the virus and quickly provided the £65,000 needed to fund the clinic for one year.

Our funding has also enabled clinicians to increase their virtual multidisciplinary meeting (MDT) from monthly to weekly, allowing them to offer advice and guidance to colleagues throughout the UK who are trying to cope with the increasing numbers of patients affected by suspected neurological complications of Covid.

Led by consultant neurologists Dr Patricia McNamara and Dr Mike Zandi, the clinic supports patients who have needed help after discharge from hospital as well as patients who have not been hospitalised but need access to care for the long-term consequences of the virus.

Author and poet Michael Rosen has been in the news talking about his own personal battle with Long Covid, and was kind enough to talk to us about his experiences. He is delighted that a specialist clinic has opened up at Queen Square and says, 'I got Covid in March 2020 and now I can't really see with my left eye, hear with my left

ear, and I have numbness in my toes. Many others have worse symptoms. I'm over the moon that The National Brain Appeal has funded this clinic because help is need for the thousands of us affected.' You can watch Michael's full message on our YouTube channel at [youtube.com/c/NationalbrainappealOrg](https://www.youtube.com/c/NationalbrainappealOrg)

Congratulations!

National Brain Appeal Trustee Professor Alan Thompson has received the 2020 Sobek Research Prize for his research efforts in the field of multiple sclerosis (MS). This award of 100,000 Euros is the highest in Europe and shows just how well he's regarded in the global MS community. He has focused his lengthy career on the care and treatment of people with MS, especially primary progressive MS, where he has been instrumental in using magnetic resonance imaging (MRI) to determine more precise criteria for diagnosis. His work has opened the



Prof Alan Thompson

way to understanding the complexities of progressive forms of MS. We are extremely grateful for his ongoing support as part of our board!

We also want to say a huge well done to Professor Rickie Patani, who is one of this year's winners of the Brain Sciences Young Investigator award. The award recognises his outstanding contribution to the field of neuroscience. Rickie is a physician scientist who splits his time between his lab at the Francis Crick Institute and the UCL Queen Square Institute of Neurology, where he is a Professor of Human Stem Cells and Regenerative Neurology. He is also a consultant neurologist at The National Hospital. Rickie is co-leading on the new stem cell facility alongside Professor Selina Uray, which we will be fully funding as part of the New Home for Neuroscience Appeal. His lab focuses on diseases of the nervous system, specifically motor neuron disease (ALS) and dementia.

Epilepsy innovation

The National Hospital is the UK's leading adult epilepsy surgery centre, and since 1990, over 1,000 individuals have had neurosurgical operations for their epilepsy.

Drug therapy for epilepsy doesn't work for roughly one-third of all patients. Neurosurgery is an option for some people if the seizure focus can be accurately localised within the brain. Critically with open surgery, the seizure focus must be surgically accessible to be removed. This means it is often too risky to offer surgery to patients with deep targets and those close to functions such as speech, sight, movement, hearing and memory.

Now, a new treatment for life-threatening uncontrolled epilepsy is about to be introduced at The National Hospital. Laser interstitial thermal therapy (LITT) is a new form of minimally invasive 'keyhole' surgical treatment for epilepsy. This involves the use of a specialised laser catheter directed by a robotic guidance device through a small hole made in the skull to treat the part of the brain that is causing seizures with heat, without the need for open surgery.

The National Hospital will soon be the UK's first adult epilepsy centre to offer this treatment to patients. Professors Andrew McEvoy and John Duncan and Dr Anna Miserocchi will lead

Prof Andrew McEvoy, Dr Anna Miserocchi and Prof John Duncan



this service, and use special navigation software EpiNav™ developed in Queen Square to find the safest trajectory to the target and minimise the risk and complications from the procedures. The team hope that this surgery, which can be performed as a day case, will open up curative surgical treatment to the wider epilepsy patient population.

New support groups

Rare Dementia Support is pleased to announce that two new support groups have been added to its virtual offering. There is now a group for Young Onset Alzheimer's Disease (YOAD) and another to support young adult children – who may also be the carers of people living with a rare dementia. The personal and social consequences of young-onset dementia can be very different than those experienced by people diagnosed with dementia later in life.

People living with young-onset dementia are often still working at the time of diagnosis, are physically fit, and may have dependent children or parents at home. They may have major financial commitments like a mortgage that they are looking to pay off. Many people affected by young-onset Alzheimer's Disease are often diagnosed and then left without support or offered inappropriate options. RDS would like the support group to be shaped directly by those living with YOAD and their families. [nationalbrainappeal.org/RDS](https://www.nationalbrainappeal.org/RDS)

For further information about RDS groups please visit [raredementiasupport.org](https://www.raredementiasupport.org)



We are hopeful for an increase in group events once restrictions ease. For now, we are offering a mix of virtual and in-person events – please join us!

Springtime challenges



To help get you active as the weather improves, we've launched two of our own challenges!

Neural Pathways is a walking challenge and there is also a new swimming challenge called BrainWave.



Lots of our supporters have already taken on Neural Pathways and raised almost £5,000! We've had to wait until restrictions lift to launch BrainWave – but now it's full steam ahead.

For both of these events, you need to:

- **Swim** either 6km, 16km or 60km (in fact, take on whatever distance you fancy!) or **walk** 26.2 miles and track your progress online, using our London Marathon route map!
- **Choose** a local pool or outdoor swim centre if you're swimming for us, or opt in to walking the 26.2 miles via our online London Marathon route map.
- **Decide** if you want to fundraise alone or as part of a team. Please make sure you adhere to the latest social distancing advice if you are a part of a team.
- **Read** our National Brain Appeal fundraising pack and pop on our T-shirt when it arrives in the post.
- **Aim** to raise at least £60 for us – all monies raised will go towards supporting key projects at Queen Square.
- **Sign up** by emailing alexis.gebbie@nhs.net or at nationalbrainappeal.org/events

Get ready, London!

The Marathon returns to the capital this Autumn.

Unusually, this year's London Marathon will take place on 3 October, instead of in April. This will give the event organisers the time they need to put on a safe and enjoyable version of the marathon we all know and love and we are really looking forward to it!

Many of our 16-strong team are those who missed out on running in 2020, when the marathon was cancelled due to the pandemic. We are delighted to have staff from the Dementia Research Centre, The National Brain Appeal and our favourite dedicated marathon-running neurosurgeon, Mr Neil Kitchen – and this year for the first time, his son Jim will run alongside him.



Neil says, "I'm looking forward to running my 10th London Marathon in aid of The National Brain Appeal. This time, I'll be joined by my son Jim which will give me an extra push to keep up. We've been doing a fair few training runs during lockdown along with our dog, Victor (who's named after the famous pioneering neurosurgeon, Victor Horsley)." You can support Neil by donating at justgiving.com/fundraising/neilkitchen21

If you missed out on a place in the event and would be interested in running the Virtual London Marathon, please apply! Sign up at nationalbrainappeal.org/events

Dates for your diary

June

- 15: Christopher Spborg Memorial Lecture

July

- 16: A Letter in Mind entry deadline

August

- 1: London Landmarks Half Marathon

September

- 26: Berlin Marathon

October

- 3: Virgin Money London Marathon and Virtual London Marathon
10: Royal Parks Marathon

November

- 3: A Letter in Mind sales preview
4: A Letter in Mind opens

December

- 5: London Santa Run
TBC Carol Concert

Get your fundraising total – matched!

A donor's generous offer has enabled us to double 10 fundraisers' efforts.



We have been fortunate to receive a sizeable donation from a grant-making trust towards our appeal to create the world's first Centre for Rare Dementias. The trust would like us to use this gift to incentivise fundraisers to support the appeal.

If you take on a fundraising challenge or host an event for this appeal and raise £5,000, this will unlock a further £5,000 donation.

This offer is available to the first 10 fundraisers and is a great opportunity to maximise your support for this exciting project, so please help to spread the word.

A number of people have already taken up the offer and are thrilled that they have doubled their total!

If you're not quite sure what kind of event or challenge you fancy, don't worry, there are lots of ideas on our website at nationalbrainappeal.org/fun-raise. Once you've decided, you simply need to email alexis.gebbie@nhs.net to let her know you're interested in taking up the matched funding offer.

Find out more about the new Centre at nationalbrainappeal.org/RDS-Centre

Talking neuroscience

You are invited to our sixth Christopher Spborg Memorial Lecture.

Taking place at 6.30pm on Tuesday 15 June 2021, this year we will be hosting the event online. The theme is 'A Research Hospital for the 21st Century' and we'll be revealing

the plans for our £7million commitment to UCL's exciting new neuroscience centre.

Bringing together research scientists, clinicians and patients, this new hub of expertise will house a world-leading facility for dementia and neurological disease research, with more than 500 neurological research scientists from UCL Queen Square Institute of Neurology and the UK Dementia Research Institute.

Speakers include consultant neurologist and charity Trustee, Professor John Duncan, physician scientist Professor Rickie Patani and Professor of Neuroradiology Tarek Yousry.*

This is a free event. If you would like to attend, please register online at nationalbrainappeal.org/events

*Please note speakers may change due to last-minute clinical commitments.



To register your interest for 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



A Will for good

We are extremely grateful for every legacy gift left to us, whether big or small.

Each gift enables us to offer more support to advance the field of neurology and neurosurgery. Even leaving just 1% of your estate can, and will, make a very real difference.

Making a Will is the only way to be sure the people and causes you care about are looked after. To make the whole process straightforward and cost effective, we have teamed up with two organisations to help you – Bequeathed and The Goodwill Partnership.

If you have any questions about leaving a gift in your Will to The National Brain Appeal, please contact Anna MacLeod at anna.macleod3@nhs.net

bequeathed
free wills, valuable advice

the Goodwill Partnership

Bequeathed is a free service – it offers detailed guidance to help you consider everything you need to think about when making a Will, and to identify any issues where expert legal advice could be valuable. If you want legal advice at any stage, just ask.

You can get a Will in three steps:

- 1 Use the Bequeathed online Will interview to create a draft will in around 25 minutes.
- 2 Attend an appointment of up to 30 minutes either in person or over the phone with a legal firm to review your needs.
- 3 Sign your Will in front of witnesses and return it to the firm for free secure storage.

Find out more at bequeathed.org/tnba

The Goodwill Partnership is the largest distributor of home-visit solicitor provided Wills in England and Wales.

The process of making your Will is made extremely simple. There are no visits to the solicitor – a trained counsellor comes to your home to take your Will instructions at a time you choose.

There is a low, fixed price of £108 + VAT, however detailed your Will, wherever you live, with no hidden costs or upsell of any other products.

Their home-visit service is free of charge and they also provide a small discount on a second Will for your spouse or partner. Visit thegoodwillpartnership.co.uk/the-national-brain-appeal

Contact and payment details

Title _____

Forename _____

Surname _____

Address _____

Postcode _____

Telephone _____

E-mail _____

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
- ☐ Please tick the box if you would like to receive email updates about our fundraising activities, events and the latest clinical breakthroughs
- ☐ Please send me information on leaving a gift in my Will

Privacy Policy

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Please return this form with your donation to:

The National Brain Appeal
3rd floor, Ormond House
26-27 Boswell Street
London WC1N 3JZ

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

THANKS



Chief executive Theresa Dauncey

Virtual team success

On a blustery Sunday in October, eight runners set out to complete the Virtual Virgin Money London Marathon. After the disappointment of the 2020 race being cancelled, Theresa Dauncey, Francois De Lange, Alexis Gebbie, John Hagues, Bruce Jacob, Eamonn Kearney, Anne Rodger and Neal Tarr completed marathons in their local areas. The team did incredibly well and raised a whopping £23,000 in the process. Congratulations all!



Stevie Howlett

Birthday fundraiser

Stevie Howlett decided to celebrate a quieter birthday in October by taking on a solo half marathon. After realising the impact that Covid-19 was having on NHS services, Stevie decided to help by running 13.1 miles and raising £400 – thanks for your support!

Shielding cyclist

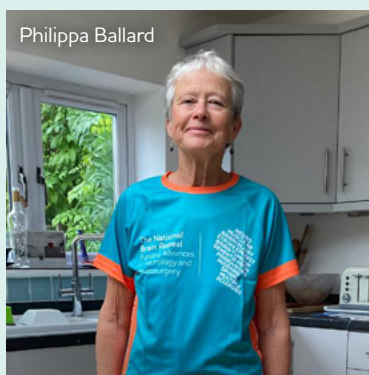
Sarah Stevens decided to keep active while shielding due to the Covid-19 pandemic by challenging herself to virtually cycle 280 miles from Hertfordshire to South Shields. Sarah absolutely smashed her challenge and completed the distance in 33 days, raising a fantastic £600 in the process! Congratulations Sarah!



Sarah reaches her target

A marathon walk

Past patient Philippa Ballard decided to walk the famous marathon distance in October, raising more than £2,000. Although a tough challenge, Philippa kept in mind the reason she was taking on the distance, "I thought of all of the support I had received from my friends and the money that would go to The National Hospital, and that gave me the energy to carry on." Well done Philippa.



Philippa Ballard



Lizi Hislop

Run for advent

Each day throughout Advent, Lizi Hislop pulled on her running shoes and went for a run and asked for donations to be made to the Dementia Research Fund in memory of her mum, Sue. Lizi raised £800 and is pushing herself further by joining our 2021 London Marathon team! Well done Lizi and we're looking forward to cheering you on at the London Marathon!



Jane Walker

50 at 50

Jane Walker celebrated her 50th birthday in style by running an impressive 50km across her birthday weekend! After her treatment at The National Hospital five years ago, Jane wanted to give something back. Instead of gifts, Jane asked her family and friends to sponsor her challenge and she raised a brilliant £1,500. Amazing effort, Jane!

Fab four

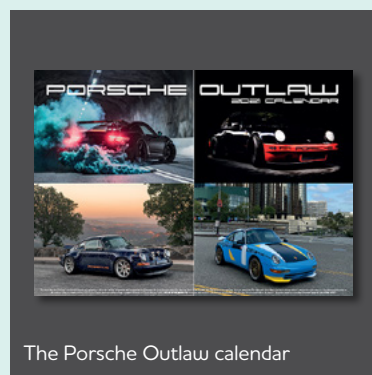
Four amazing runners took on the Virtual New Year run, covering a marathon distance of 26.2 miles throughout January. A huge well done to Stephanie Jones, Lauren Dawson, Amy Pickles and Douglas Pickles for completing the challenge, raising a total of £1,860 towards the new Centre for Rare Dementia Support. The team received an extra £1,500 matched funding towards the centre too.



Stephanie Jones

Power to the Porsche!

It has been another successful year of calendar sales! A huge thank you to the Ghost Outlaw, for creating the 2021 version of the Porsche Outlaw calendar, which was ordered far and wide across Europe and the USA! This year's calendar raised a wonderful £2,650 for our FTD Research Fund.



The Porsche Outlaw calendar



Colin Stone

A musical celebration

Thank you to supporter and pianist Colin Stone who recorded a virtual concert to celebrate Beethoven's 250th birthday. Colin very kindly allowed us to offer this performance in exchange for a donation to The National Brain Appeal and it went down a treat!

Rare Dementia Support

A Christmas tune a day

Thank you also to Helen Moffatt who created a musical advent calendar to raise money for Rare Dementia Support. Helen, a music teacher, accompanied by flautist Emma, treated us all to a festive performance throughout December, bringing some welcome joy throughout the month!

Charity of the Year partnership

We're excited to announce that construction and labour supply company the Danny Sullivan Group (DSG) has chosen The National Brain Appeal as their Charity of the Year for 2021!

Company founder and chairman Danny O'Sullivan (right, with son Tim) had a life-threatening brain haemorrhage from a ruptured aneurysm back in 2017 and the team at The National Hospital saved his life. He spent five months in hospital in total and had to re-learn how to walk and talk.

Danny's son and managing director of DSG, Tim O'Sullivan, along with his wife Kacey, have raised over £80,000 for us in recent years and most recently donated £5,000 to the charity's Emergency Fund for the hospital at the start of the Covid-19 pandemic in April 2020.

Tim says, "Seeing my father doing so well now is testament to the incredible skill and expertise of the staff at The National Hospital. My family and I are grateful every day for returning him to such

good health that he can live and enjoy a normal life. The National Brain Appeal is a charity very close to our hearts and we are delighted to announce a year-long partnership to raise money and awareness for this fantastic charity."

If you know a company or business that would be interested in partnering with us through our corporate programme, email us at info@nationalbrainappeal.org No matter how small or large the company, we'd love to hear from you!



Danny and Tim O'Sullivan