

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

Newsletter
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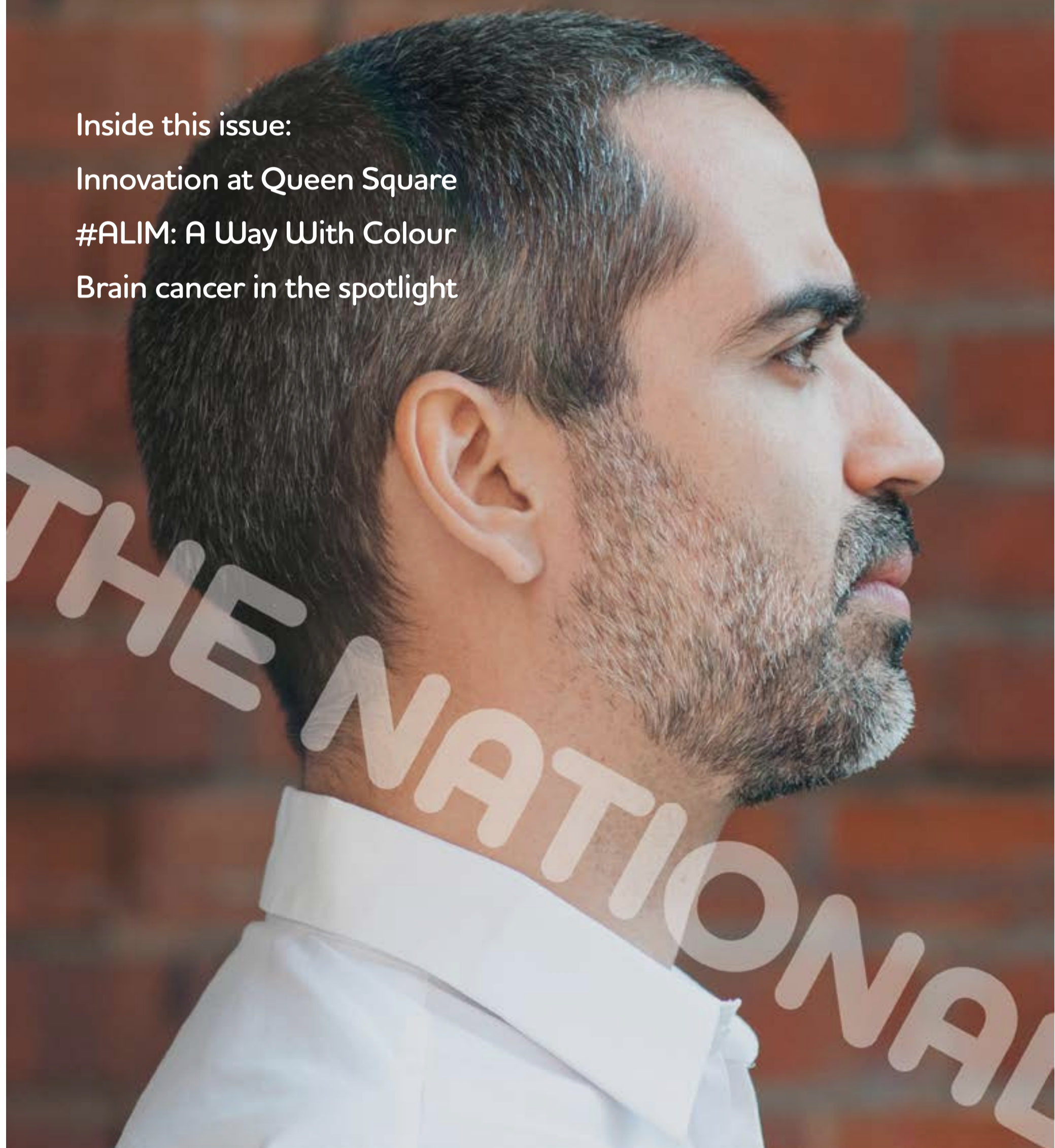
NEURO
MUSCULAR
BRAIN INJURY
STROKE EPILEPSY
BRAIN TUMOUR
DEMENTIA PRION
PARKINSONS
MIGRAINE
SPINAL
MULTIPLE
SCLEROSIS

Inside this issue:

Innovation at Queen Square

#ALIM: A Way With Colour

Brain cancer in the spotlight



UPDATE



(L-R) Jane, Alexis and Abbie

Focus on... CIDP

Many rare conditions are treated at Queen Square. Here we look at Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

What is it?

This is a rare disorder of the peripheral nerves – they are stripped of their fatty protective coating called myelin, which slows down the messages to the brain.

Symptoms

These vary, but the main symptoms are:

- Loss of sensation in arms/legs
- Abnormal sensation (altered)
- Weakness in arms or legs
- Loss of reflexes

The treatment

Unfortunately there is no cure for CIDP at present, but Laura Compton, Neuromuscular Immunology Nurse specialist, explains, "With careful management we can often get symptoms under control to help people live a normal life. Intravenous Human Immunoglobulin Infusion (IVIg) is the most common treatment. This is an infusion which can be given into a vein or under the skin. Most patients receive this infusion every few weeks, and

we tailor the correct treatment dates to their needs.

Some patient's symptoms are almost non-existent following their infusions, however regular treatment is key to maintaining stability with this condition. Some patients will still experience symptoms of CIDP following treatment, but they are usually far less severe following an infusion.

The clinic in Queen Square

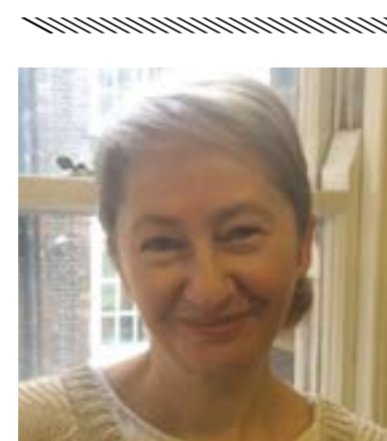
"We see about 120 patients for regular IVIg treatment for CIDP at The National Hospital," says Laura. "Patients travel from across the UK to be seen by our consultants, and many choose to have their treatment here in our Day Care Unit. We also have patients who receive IVIg infusions at home which mean that they come to see their consultant every six months rather than attend for regular infusions."

David Barttelot (below) was in his late 40s when he was diagnosed with the condition.

"I knew something was wrong – I got double vision, which caused difficulty in driving. My writing was poor. I started to drop things. I had difficulty doing up my shoelaces and shirt buttons, and I began to walk on the sides of my shoes. During the IVIg treatment you can actually feel your hands and feet getting better. You suddenly feel a burst of energy. My vision has returned to nearly normal too. These days I walk with the aid of a stick outside, and there is a need for frequent stops to sit down, but I am extremely grateful for the care I receive here. The Day Care staff are professional, understanding, and have a good sense of humour!"



"You get a burst of energy"



What's your role at the hospital?

I'm a rota coordinator, which basically means I look after the doctors during their placement here for their junior neurology rotation. I manage their daily on-call responsibilities, and organise the changing of placements during the year. I also coordinate their annual and study leave.

What is your average day like?

Extremely busy! Each day I have to ensure we have enough doctors across the board to avoid safety issues in the hospital. This means adjusting rotas when people call in sick or have leave. I need to move people around to make sure we have the correct cover. It's a juggling act!

It sounds like it can be a challenging role...

It can be a real tightrope to get the balance right. As a Trust, we need to be aware of how much we spend on locums. I work really hard to use existing staff to plug any gaps in the rota. The current financial situation is very challenging, so if I can try to keep costs down, it all helps.

What's the best bit?

The doctors. I do it for them – I see every day how hard they have to work. They have so much responsibility at such a young age, I am always so impressed by them.

The bottom line is that they are here saving lives. If I can keep them happy, I've done my job.

Unsung Heroes of The National Hospital

Virginia Joy, Rota Coordinator – Junior Neurology

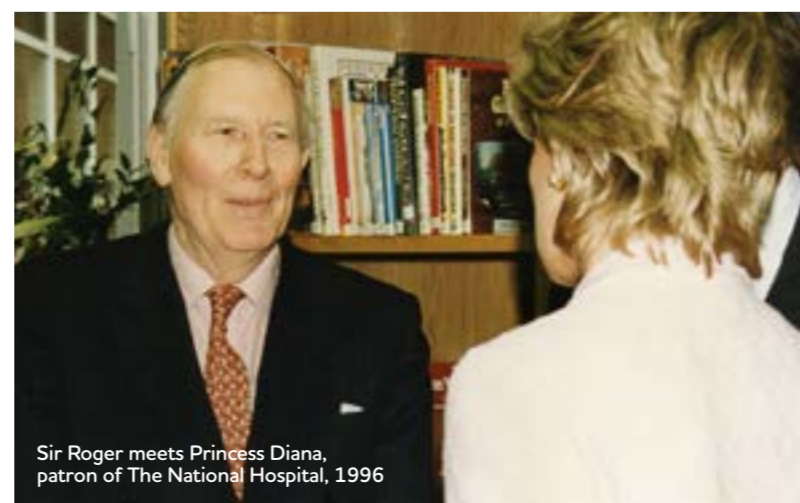
Sir Roger Bannister, 1929-2018

Sir Roger Bannister was best known to the public as the first person to run a mile in under four minutes, but here at Queen Square, he is best remembered as a renowned consultant neurologist. In fact, when he was asked in an interview which achievement he was most proud of – his running fame or his clinical career – he replied that he was prouder of his contribution to medicine.

He led the way in the specialty of autonomic neurology (the autonomic nervous system unconsciously controls all the automatic systems of the body from digestion to the heartbeat) and set up a specialist unit at Queen Square.

His legacy continues to thrive and the unit has expanded with consultants, clinical scientists and specialist nurses. The team manages an active research

programme and a busy clinical service, treating several thousand patients each year – and all as a result of the innovation and brilliance of Sir Roger Bannister.



Sir Roger meets Princess Diana, patron of The National Hospital, 1996

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



Neuro-rehab in the spotlight

Recently The National Hospital featured in two fascinating documentaries shining a light on stroke recovery issues. Richard Gray was the subject of BBC2's *Horizon: Richard's War*. The programme followed his recovery after a catastrophic stroke and showcased the incredible work being done by the neuro-rehab unit at Queen Square. Consultant neurologist Professor Nick Ward and other colleagues in the clinic are seen supporting Richard to regain his mobility and independence.

Professor Ward says:

"Our upper limb neuro-rehabilitation programme provides high quality, individualised care to patients who have suffered a stroke. The emphasis is on getting people to use their affected arm and hand again in their daily routines. Intense physical therapy can make a meaningful difference even for people who have been told that further recovery wasn't possible."

The National Brain Appeal has supported a number of neurorehabilitation projects for the upper limb service through the Small Acorns Fund and has committed £1.5million to improve stroke care at Queen Square.

The neuro-rehab unit was also featured in a BBC Four documentary, *Speechless*. Two men – Junior and Barry – both used the services at Queen Square to help them with their aphasia. This is when the part of the brain which is involved with speech becomes damaged. They learned to speak again with the help of the highly-trained staff at The National Hospital. During the making of the programme, one of the assistant producers

on the documentary, Laura Sunnucks, was so inspired by the work that she saw in the unit that she decided to change careers to become a language therapy assistant and is now part of the team in Queen Square!

Huntington's breakthrough



A dangerous protein builds up in the brain

Huntington's disease is one of the most devastating neurological illnesses. Some describe it as a combination of Parkinson's, Alzheimers and MND rolled into one. There is currently no cure, but in December 2017, researchers at The Institute of Neurology made a huge breakthrough. They found that they could successfully lower the levels of a dangerous protein, called huntingtin, in the brains of those affected by the disease. On the trial, 46 patients had a 'gene-silencing' drug injected into the fluid that bathes the brain and spinal cord. This first human trial showed that the drug was safe and well tolerated by patients. Professor Sarah Tabrizi led the trials and says, "I've been running a clinic for nearly 20 years and have seen many of my patients over that time die. For the first time we have the potential, the hope, of a therapy that one day may slow or prevent Huntington's disease. This is of groundbreaking importance for patients and families."



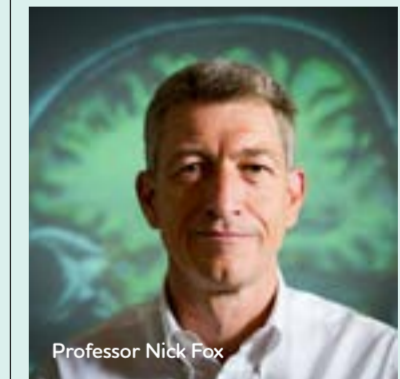
Members of Lane Fox family at the opening of the new unit

Early signs

A team led by Queen Square researchers has developed a test to spot subtle deficits in memory, years before actual Alzheimer's symptoms develop – giving real hope that the disease could be detected early.

The study involved 21 people who carried the gene mutation for early-onset Alzheimer's alongside healthy control subjects. All underwent a memory test with 30-minute recall, and were then checked seven days later to see if they still remembered.

The researchers found that people who were closest to the expected onset of symptoms could remember things after 30 minutes, but then had forgotten things after seven days. This shows memory formation isn't the issue, so typical tests won't spot problems. The test could help identify people for early clinical trials, while helping monitor whether a treatment is working.



Professor Nick Fox

"It's really a case of accelerated forgetting," says Professor Nick Fox, study lead. "Many people have a feeling that something is going wrong with their memory, but when they take the current test, it doesn't show anything – 30 minutes isn't enough time. The people who carried the mutation did no worse at 30 minutes but at seven days they were quite a lot worse. The difference was really quite remarkable."

"Every three minutes someone in the UK develops dementia. There is always an urgent need for people – healthy or affected by dementia – to take

part in trials. Interested? Visit joindementiaresearch.nihr.ac.uk

Brain tumour ward opens

The Molly Lane Fox Unit, which was the first dedicated ward for brain tumour patients in the UK has now been expanded and was officially opened in January.

The original unit opened in 2011 with £1m funding from our supporters, but was such a success, with 750 patients being seen on the ward each year, it became clear that extra capacity would have to be found to meet the demand. We raised almost £670,000 to help the new ward to relocate and expand, and it now has 26 beds.

The opening event was attended by many key fundraisers for the project including members of the Lane Fox family, Clíodhna McCorley who organised A Night for Life ball with all proceeds to the unit, and many more. The new unit is now fully operational and will provide a clinical hub of expertise for those affected by brain cancer, including recruitment on to innovative clinical trials to explore new treatments (see our Immunotherapy Appeal on p3).

New chair

Welcome to Lord Prior who is our new UCLH Trust Chair. "I am delighted and feel very honoured to be joining UCLH," says Lord Prior. "The future is going to be more fascinating; gene and cell therapies enabling personalised medicine; digitisation; the impact of artificial intelligence, big data and machine learning; much earlier diagnostics and prevention of chronic disease; and electronic patient records to name just a few of the forces that will affect the way we deliver care over the next 20 years. These are exciting times and UCLH is uniquely positioned to help lead these changes in the NHS."

"Intense physical therapy can make a meaningful difference, even for people who have been told that further recovery wasn't possible"

Prof Nick Ward

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

THANKS

#PowerCouple



Kacey & Tim

Timothy O'Sullivan and Kacey O'Driscoll pedalled their way across Britain raising an astounding £80,000 in the process! They decided to take on this challenge after Tim's father, Dan, had a severe stroke last summer and spent many months at The National Hospital. They cycled 969 miles from Land's End to John O'Groats, riding an average of 108 miles a day. They climbed about 50,000ft over nine days – that's almost twice the height of Everest! Tim says, "It was an incredible adventure and a real test of our minds and bodies. Each day brought different challenges but being a part of one of the most iconic cycle rides has been an incredibly rewarding experience."

Victorious veganuary



Emma Chandler

At the start of this year, Emma Chandler challenged herself to go vegan for January and has raised over £3,000 for our Rare Dementia Support Fund. Emma says, "I decided to do Veganuary because everyone knows how much I love a good steak. So I thought I'd put myself through my version of torture for a month for a great cause. I'm still in shock as to how generous everyone has been!"

On top of the world



Andrew Gilvary

Andrew Gilvary trekked 160k to Everest Basecamp in December and raised over £2,600 for our Rare Dementia Support Fund. Andy said, "Having seen the effects dementia can have, and the love, care and challenges that come with it, the support of The National Brain Appeal is much needed by those who are surrounded by the disease." Congratulations Andy!

Family ties



Darryl Lyle

In October, Darryl Lyle ran the Amsterdam Marathon and raised over £3,800! Darryl ran in memory of his late sister, Rochelle, and her baby daughter. He said that he was able to channel his grief into his running, "I have been able to raise money towards important research that I hope will help prevent anyone from going through the struggle we've had."

Hitting the wall

Aimee Jennings raised an incredible £4,600 by trekking The Great Wall of China in October. Aimee raised money for our Molly's Fund Appeal, after her dad stayed on the hospital's brain tumour ward several times. She said, "The hospital has provided him with

over 20 years' of outstanding care, ranging from regular MRI scans to life-saving brain surgery. I have always wanted to trek the Great Wall of China,



Aimee Jennings

so felt this was the perfect opportunity to get involved with a fantastic charity and give something back." Thanks Aimee!

Summer fun day



Masterman FC

Masterman Football Club hosted a friendly against DC Mexico in August followed by a family fun day, which raised over £3,700! Thank you to everyone who made this day such a runaway success! The organisers of the football match said, "We organised a football match on 27th August for the Martin Pain Charity Shield; created in the name of our former skipper who sadly passed away from a brain tumour. Martin always spoke fondly of the doctors and nurses. We wanted to raise some money for the hospital that tried so hard to keep our friend alive."

Festive vibes

On a cold, drizzly morning in December, a small team of fundraisers donned their Santa suits and ran through Victoria Park in London. A huge thank



Our Santa Runners!

you to Tina Wells, Joanna Hickey, Julie Hogg, Sarbs Carter and Clíodhna McCorley for raising nearly £1,000! Joanna, who suffers from epilepsy and had brain surgery in 2011 said, "After learning to walk and talk again, it's simply my way of saying thanks and I'm a huge supporter of The National Hospital."

Royal runners



#Team Brain Appeal 2017

Our 22 Royal Parks runners collectively raised £25,000 – a truly amazing effort! We're so proud of all our runners who took on the half marathon. Thank you to: Andreia Aguiar; Mark Bentley; Daniel, Mark and Matthew Bumpstead; Harriette Coates; Nicola Coles; Alex Duncan; Daniel Egleton; Simon Finch; Thomas Hallam; Flo Hanson; Jo Hislop; Adam Hust; Daisy Knibb; Anthony Maguire; Ben Malbon; Alex Mollin; Clare Reynolds; Craig Saccente-Kennedy; Jonathan Schott and Joanna Smith for your efforts!

Saddle superheroes

Well done to our fantastic Prudential Ride London team who cycled 100 miles and raised a wonderful £6,250! Thank you to: Leanne Gallagher; Robert Hill; Dr Michael Lunn and Jenni McGivney for their epic pedalling

efforts. Dr Lunn, who works in the Centre for Neuromuscular Diseases at Queen Square said, "Having cycled to Brussels in aid of The National Brain Appeal in 2016, I decided that the Surrey Hills looked appealing. And what better a charity to support than one that supports our patients and the work of our hospital?"

In deep water



Alla, Claudia & Kate

In September, four of our amazing fundraisers dived into the Serpentine in Hyde Park and swam half a mile! A big thank you to Claudia Bullmore, Alla Murphy and Kate Samad from Bindmans LLP who raised over £2,100 and to Lucy Harley Mckeown who raised £900.

Green fingers



Maureen Steward

Maureen Steward has been selling plants from her home to raise money for The National Brain Appeal for an astonishing 11 years now! She has almost hit the £10,000 mark and says, "I grow them and then each May I start to sell. I attract people with colourful hanging baskets and patio planters. I'll go on until I'm unable to. I know it makes a difference." What a star!

Magnificent Munnelly Group

We are extremely grateful to the employees at The Munnelly Group and to the Munnelly family for choosing to support The National Brain Appeal. Since October 2017 they have raised a phenomenal £11,000 through an annual client golf challenge and Christmas Jumper day at their Harrow office. We are looking forward to working with them more over the next year and to build on their fundraising success.



Munnelly Group's golf day raised £10,000

Sparkling efforts

The Maidstone branch of Beaverbrooks is made up of eight enthusiastic staff members who go above and beyond to support charities. The National Brain Appeal is lucky enough to be chosen as their Charity of the Year and they had already raised £800 by the end of January – a great start! They plan to continue fundraising for The National Brain Appeal over the year by organising cake sales, receiving donations for cleaning jewellery and much more. Thank you, Beaverbrooks!



Beaverbrooks' Maidstone team