The National Brain Appeal – Projects Update July 2020

While the pandemic has affected many of the services and care pathways that you have helped us to support at Queen Square, the team have adapted to these new challenges with a common objective – to do their best for their patients.

Since lockdown began at the end of March, many outpatient services and activities were suspended to control the spread of the virus and protect vulnerable inpatients and staff.

These have been very difficult times for all of us but despite so much uncertainty, exemplary work still continues at Queen Square and we're shining the spotlight on our six funding areas and a few key projects.

Neurology

Stroke

Stroke is the most common cause of neurological disability in the UK. The National Brain Appeal committed to raise £1.5m to create an acute interventional neuroradiology service for stroke at Queen Square. Phase 1 of the project has completed and Phase 2 – the purchase of an additional angiogram scanner – although delayed, will transform services further. Meanwhile, as the result of the pandemic, the Hyperacute Stroke Service (HASU) was transferred to The National Hospital from UCLH.

While the team noticed a reduction in strokes presenting to the hospital compared to the same period last year (probably due to fears around coming in to hospital), these numbers are now increasing. The message that they would like to share is that sudden-onset symptoms of face, arm, leg weakness or speech disturbance need to be seen and evaluated urgently – and all stroke services are fully open and ready for action.

MRI and Imaging

The ability of the neuroradiology department to see as many patients as usual was vastly reduced due to the requirements of social distancing, intensive cleaning between patients and the need to wear specialist PPE for certain procedures. In the early days of the pandemic when the hospital treated significant numbers of patients who were Covid-19 positive, efforts were concentrated on in-patients with ITU patients being X-rayed on a regular basis to monitor lung complications.

As we begin to see more complications associated with Covid-19, particularly neurological, some of our neuroradiologists are spending equal time sharing knowledge with colleagues across the world; Professor Jager has been invited to collaborate with an eminent group of experts in the United States and has just delivered a prestigious 'Stroke in Covid' lecture via Zoom. Prof Jager and Prof Yousry are also jointly heading a collaborative Neuro-Covid imaging research group, which includes centres from France, Spain and Brazil.

With less to report, members of the neuroradiology department – radiographers, trainees and consultants – volunteered to support their colleagues on ITU who were the most affected in this period. To reduce the exposure to coronavirus, the department worked with the IT team to establish home-reporting solutions, which will become a permanent fixture of their new working environment. As the hospital gradually opens up again to elective neurosurgical/neurology patients, the team are working hard to increase capacity to support this activity.

Neuropsychology

Our £205,000 appeal to support a project to digitise the complex neuropsychological tests, link them with MRI images of their brain and use them to fully assess the mental health and cognition of patients will have a huge impact on their quality of life after an illness or injury. The Covid-19 emergency led to significant changes in the Neuropsychology department. Assessments were limited to those with acute symptoms or on emergency pathways, and all therapeutic support transferred to telephone/video clinics. Despite these challenges, three new services have been developed:

1. New support services for staff, offering twice-weekly walk-in and daily telephone clinics.
2. Telephone consultations to all outpatients who had experienced delays in hospital care, or distress during this time.
3. Telephone clinics for all family members and carers affected by hospital lockdown and bereavement. Although the initial emergency has now passed, we are only now beginning to realise its legacy: for staff, patients and families.

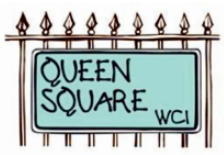
Neurosurgery

The National Hospital is renowned as a centre of neurosurgical excellence. The unit provides a local, national and international service for specialised neurosurgical problems such as epilepsy, Parkinson's disease, movement disorders and pituitary tumours. During the Covid-19 crisis all emergency surgery continued to take place and more recently the teams have worked hard on creating capacity to start seeing elective patients again and good progress continues to be made.

Neurodegeneration

Rare Dementia Support (RDS)

The charity has been fundraising for Rare Dementia Support since the service began and this year committed to raising £300,000 to develop and extend provision with an education programme, increased support and research. As part of this a new, dedicated RDS website – www.raredementiasupport.org – was launched on 29 February. Covid-19 meant the RDS team has handled double the usual number of support calls which accelerated the need for practical digital resources. In response, the Direct Support team put together Covid-related advice and support including short videos to help carers and people living with a rare dementia to cope with issues around isolation, hygiene maintenance, hospital admission, loss of day care services and essential activities. All support groups have, very successfully, moved online with high participant numbers. In addition to these, new smaller online discussion groups have been formed. These are facilitated by an RDS member to discuss issues such as independence and identity and grief and loss. And, last but not least, a new Admiral Nurse has been recruited to the team to help families facing dementia.



Queen Square

Emergency Fund

The National Brain Appeal launched its Emergency Fund to provide practical support for staff and patients during and after the crisis. £25,000+ has been raised to date – thank you! Initially set up to help provide practical support such as snacks and toiletries for staff and patients, many of these items were in fact donated by generous companies and there was no need to buy them. Some of the funds were used to buy practical clothing following emergency admissions to the neurorehabilitation unit (as patients were unable to have visitors or bring items from home) but, as the situation is beginning to come under control, the remit of the fund is evolving. We now want to support Queen Square's recovery moving forwards, as the team adapt to the new ways of working including delivering crucial services for patients while social distancing is still in force. Alongside this, Queen Square is leading on a number of research projects

examining the neurological impacts of Covid-19. We'll be updating you on how these funds were allocated soon…

Small Acorns Fund

We're delighted that we were able to continue our Small Acorns Fund activity during lockdown – albeit remotely. In the latest round in April, 10 applications were received and we were able to provide funding for nine of these projects (totalling more than £20,000) which included: the introduction of a neurosurgical biocompatible 3D printing facility for the neurosurgery team; a project to sequence muscle-wasting and changes in patients with McArdle Disease; the creation of a website to share knowledge, provide peer support and improve experiences/access to care for patients with Functional Neurological Disorder; and, the purchase of a laser cutter to improve neuroimmunology testing and provide a non-disrupted service for the 3500 patients who are tested each year.

Education and Training

Physician Associates

The National Brain Appeal provided funding for a one-year pilot scheme to employ two new Physician Associates (PAs) within the neurology and neurosurgery teams. PAs are trained healthcare professionals working closely alongside doctors and medical teams. Increasingly, they are being appointed in hospitals to provide continuity of care for inpatients. These roles are proving very successful at The National Hospital and have now been extended to the Daycare and Stroke Units. During the Covid-19 crisis the neurosurgery PAs switched to 12 hour/7 day cover, ensuring the surgical teams had support every day. They also supported their ITU colleagues with proning (turning patients on their fronts and backs when they are in an induced coma), patient care and research. At the same time, the neurology PA helped to establish the Covid ward on the Molly Lane Fox Unit and provided medical support to patients returning from ITU. Within Daycare, the PA supported the team and pivotal in keeping the IVIG patients safe and secure, helping to provide the only regular medical input for the whole service whilst the junior doctors were re-deployed elsewhere. Finally the stroke PA helped the transition of the HASU to Queen Square, and helped set up the new Emergency Stroke Unit.

Technology and Innovation

Immunotherapy

Since the trial opened in seven centres in January last year, 77 patients have been randomised into the study. New recruitment to the study was suspended because of Covid-19 but the team is continuing to monitor and collect data on those already in the study and are putting plans in place to re-open recruitment for the final 43 patients when Covid-19 is under control. Despite the temporary suspension, this has been the most successful clinical trial into brain cancer to date.

The team, led by Dr Paul Mulholland, who designed the IPI-GLIO immunotherapy clinical trial has established a Glioma Research Group and laboratory at UCL Cancer Institute and are putting together a programme of trials so this work can continue.

Aphasia

The National Brain Appeal/NHNN supported Queen Square Intensive Comprehensive Aphasia Programme (ICAP) has been running for one year so far and has treated over 43 patients with long-standing aphasia, caused by stroke, traumatic brain injury or brain tumour. Following the initial three-week intensive therapy programme all patients have made significant gains across all four of the main language domains (speaking, writing, reading and listening), with speaking and writing (language output) improving the most. Importantly, these improvements were not only statistically significant but also clinically meaningful for 77% of patients. Following the three-week programme the ICAP team continues to assess and support all patients and their families to help maintain language

gains and increase communication at home/work. So far the data indicates language improvements are maintained three months later and (by the end of August) the six month data will be analysed as well. The feedback from patients and their families has been very positive. Here is what one user's partner had to say about its impact on their lives:

"The programme was a godsend" "...it (the ICAP) pushed him to realise he could get better. Now, every day there's improvement. The programme gets them going and gets the job done… really, you just need it…It's nice to know he hasn't just had the programme and that's it, he's got you checking in and seeing what else can be done, it's really important."

Due to Covid-19, the programme has been temporarily suspended to new patients although existing patients continue with their follow-ups remotely. The aim is to restart the programme as soon as possible –restrictions pending. In the meantime, the first year's data is being collated and analysed and will be used to make adjustments and improvements to the programme when it restarts.

Innovation Fund

Two projects have been supported via the Innovation Fund to date. The first, to develop a 'smart instrument for keyhole brain surgery is being led by consultant neurosurgeon Hani Marcus. When Covid-19 hit, he returned to doing night shifts, and organised a consultant 'war-time' rota. He says "The team are really fantastic. I have always felt extremely lucky to work at Queen Square, but especially so now." Despite not being able to be physically in the lab, Hani and engineering PHD student, Emmanouil Dimitrakakis are hoping to continue work on their designs - alongside everything else! The second project, to improve the success of skull-base tumour removal led by Dr Jonathan Shapey, was put on hold along with all research other than Covid-19, or other life-threatening conditions on 16 March. Before the lockdown, they had recruited eight patients, scanned seven patients and operated on five of them. During the worst of the outbreak, Jonathan volunteered to increase his clinical work to help tackle the crisis and went back on the rota covering neurosurgery and intensive care at The National Hospital.

The latest round of funding is being assessed this month and we hope to be able to fund a new project – thanks to the ongoing support of our Ambassadors for Innovation.

Neurorehabilitation

We recently launched a new appeal to support the refurbishment of the Neurorehabilitation Unit (NRU) which provides rehabilitation for people over the age of 16 with the most severe life-changing brain and spinal cord disorders. This will create a much improved (and fit for purpose) environment for all NRU users – patients, staff, family members and visitors. Work was due to start this summer and although there has been some delay, it is scheduled to begin in the next few months and should complete before Christmas.

During the Covid-19 crisis, the unit changed its admission criteria to support patient flow across UCLH, namely stroke and post-operative neurosurgical patients. This has been incredibly helpful in managing those patient pathways.

Thank you once again for your support

We hope that you have found this update useful – please keep an eye on our website for further news and developments. Some services have been transformed for the better by the challenges faced and some will take longer to get back to normal. The situation continues to change and we are keeping in close contact with the management team and QS clinicians about the impact on our funding areas – it goes without saying that this will be a marathon not a sprint.