The National Brain Appeal
Funding advances
in neurology and
neurosurgery Report and Accounts



# Financial Statements for the year ended 31 March 2021

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The National Hospital for Neurology and Neurosurgery Development Foundation (also known as The National Brain Appeal)

A company limited by guarantee

#### Chair

Jackie Ashley

#### Treasurer

Diarmid Ogilvy

# Chief Executive/ Company Secretary

Theresa Dauncey

#### Charity Registration Number

290173

#### Company Number

01844281

# Principal Address and Registered Office

The National Hospital Queen Square London WC1N 3BG

#### Statutory Auditor

Moore Kingston Smith LLP Devonshire House 60 Goswell Road London EC1M 7AD

#### **Solicitors**

Charles Russell Speechlys LLP 5 Fleet Place London EC4M 7RD

#### Bankers

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#### **Investment Managers**

Schroder & Co Limited 31 Gresham Street London EC2V 7QA

Cover image: Artist's impression of UCL's new neuroscience centre on Gray's Inn Road which will include a sensory garden, a courtyard and plenty of green space. All rights reserved by UCL.

# Trustees' Report

# Trustees' Report

The Trustees, who are the directors of the charitable company, present their report and the audited accounts for The National Hospital Development Foundation (the Foundation) for the year ended 31 March 2021. The charity's working name is The National Brain Appeal. The financial statements comply with current statutory requirements, the memorandum and articles of association and the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities".

#### **Status and Objects**

The Foundation was incorporated on 29 August 1984 and is a company limited by guarantee with charitable status. It is registered as a charity in England and Wales, number 290173.

The Foundation has been established to promote the relief and prevention of diseases of the nervous system. Funds raised by the Foundation are to be used for the erection and maintenance of buildings, the purchase and maintenance of medical equipment, for education and for clinical research.

#### **Public Benefit**

We have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing our aims and objectives and in planning our future activities. The Charity supports a range of activities to advance treatment of and research into neurological conditions which is clearly of public benefit.

#### Governance

The Trustees determine the direction and policy of the Foundation in response to requests from The National Hospital for Neurology and Neurosurgery (NHNN) and the UCL Queen Square Institute of Neurology. The members are elected by Council (which comprises the directors of the company) to serve a period of three years and are unremunerated. There are normally between 11 and 15 Trustees and they are recruited by recommendation, advertisement and interview (and in the case of the Chair, with the services of a recruitment agency). Ad hoc committees, which include the Trustees, are formed to run periodic special events. The Trustees, who meet six times a year, have delegated the day to day administration of the Charity to the Chief Executive, Theresa Dauncey. The Chief Executive has regular meetings with the Chair and Treasurer. The Chair determines the salary of the Chief Executive.

#### Investment powers

Under the memorandum and articles of association, the Charity has the power to make any investment the Trustees see fit.

A Sub-Committee of the Trustees monitors the Charity's investments and reports annually to the Board.

The policy for invested funds focuses on maximising income. The performance for the year was considered satisfactory.

#### Charitable aims

The mission of The National Brain Appeal (TNBA) is specific – namely, to fund advances in neurology and neurosurgery. By focusing its efforts on The National Hospital for Neurology and Neurosurgery and the UCL Institute of Neurology (known jointly as Queen Square), it is funding the leaders in the field – whose work has both national and international impact.

Our vision is to improve the outcome and quality of life for all those affected by a neurological condition. We achieve this by funding pioneering research, providing access to the best technology for expert diagnosis and treatment, and training tomorrow's leading clinicians.

The Trustees select projects which will have the biggest benefit for people with neurological conditions and which are innovative in nature. The Charity holds a number of funds to support work for a variety of neurological conditions but the main focus is on major capital and research projects which will have a transformative effect on the services provided.

Since the charity was formed, 37 years ago, it has had a huge impact on the development of Queen Square, providing in excess of £45million of funding for all of the major capital projects at The National Hospital over this period as well as a great number of translational research initiatives.

In 2020, Trustees endorsed a growth strategy to build the Charity's income to around £10million over the next three to four years in order to deliver larger charitable projects, including two major capital appeals (detailed later in this document). Investment in staffing, systems and digital activity has already commenced and the strategy for 2022-25 will be developed and agreed over the coming year.

# Review of the year

This financial year saw total voluntary income increase from £1,763,825 in 2020 to £3,125,026 in 2021. This was mainly due to an increase in income from grant making trust and legacies and an increase in donations from individuals. This was despite a significant drop in income from all types of events which were affected by the Covid-19 pandemic.

The cost of raising these funds was £639,840 compared to £568,489 in 2020. This was due to increased investment in staff and a new donor database in preparation for a growth in fundraising activity.

Our total funds currently stand at £7,788,598 with £3,738,731 million ring-fenced in restricted funds and £2,650,833 designated for specific projects as described later and detailed within the designated and restricted funds sections of the accounts.

As for everyone across the world, the year began with a great deal of uncertainty in every sense. The Trustees and Executive team fully expected a big drop in income and our plans were amended accordingly. It was decided to make the most of the opportunity to make some governance and infrastructure changes which it had been difficult to plan and implement in normal times.

On the governance side, Jackie Ashley was recruited remotely (by Zoom) and appointed as the new Chair in May and four new Trustees were recruited and a new President role was created.

The Governance Code was adopted and a number of sub-committees were established. Now work is underway to evaluate whether the Charity is delivering the principles of the Code and to take steps where this is not the case. The infrastructure changes were extensive and included the transferal to a new accounting system, the introduction of a new database and new credit card processing, all alongside a move to remote working for everyone. In addition, nearly all our publications and materials were updated and a lot of our fundraising went either online or via telephone, where the team were able to test new activities and approaches with great success.

In the event, we not only upgraded nearly every area of activity (while working with completely new systems and remotely) but our original pre-Covid income target was achieved which has meant that no cuts have been made to any projects and we were able to approve funding for another 30 projects during the year. In fact, we are now in an excellent position to grow in order to deliver some ambitious and ground-breaking projects for the benefit of those suffering from neurological conditions.

The Trustees would like to thank everyone who has supported The National Brain Appeal over this extraordinary year. You have made it possible for us to continue to make advances in improving treatments and research, as well as supporting National Hospital staff (through the Emergency Fund) at one of the most challenging times in their working lives. We are so grateful.

# **Charitable Funding**



#### 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

Our funding is grouped into the six areas outlined above. This report focuses on our two current capital projects, a summary of the achievements from our funding of a range of brain cancer projects and profiles a few projects either recently completed or launched to give a sense of the range of activities The National Brain Appeal supports.

A full list of all the restricted funds is set out in the notes section on pages 34-36 and more details on all our active projects can be found on our website.

Not surprisingly, due to the Covid-19 pandemic, there were some adaptations and delays to projects at Queen Square. Our aim is to help support the hospital to bring delayed programmes back on track as quickly as possible. We have been working hard to ensure that funds are available to those projects most in need, while also forging ahead with plans for our ongoing appeals. The excellent news is that our income continued to grow throughout the pandemic, enabling us to continue to support an excellent range of high-quality initiatives.

# **Capital Projects**



#### Clinical Neuroscience Centre at Gray's Inn Road Project (Funding area: Queen Square)

The National Brain Appeal has committed to raise £7million towards the creation of UCL's 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 National Hospital for Neurology and Neurosurgery (NHNN).

One in six people in this country is affected by a neurological or neurodegenerative condition. These diseases include dementia, stroke, motor neurone disease, neuromuscular diseases, brain cancers, Parkinson's, multiple sclerosis and epilepsy to name just few. They account for 13% of global disease prevalence – more than cardiovascular disease and cancer combined and the annual cost to the UK is estimated to be £134 billion.

By co-locating ground-breaking neurological disease research alongside world-class translational clinical facilities, the Centre will enable clinicians and researchers to better investigate the global health challenges of these disabling and life-limiting conditions, and to quickly put new treatments into action. The Centre will be fundamental to fulfilling the Queen Square 20-year clinical vision and strategy: to establish a research hospital that is pre-eminent in clinical care, research and teaching, and aims to improve the clinical outcomes

and quality of life for every individual living with a neurological disorder.

Within the building, a range of core facilities including stem cell, genetics, gene therapy and imaging will be available to be shared by researchers across disciplines. This will enable collaboration across neuroscience teams, improving diagnostic and therapeutic advances and translating science to clinical practice – directly benefitting patients, who will be coming for diagnosis and treatment in the same building. A truly concept-to-care approach.

Providing an inspiring environment in which to train the next generation of translational neuroscientists is central to this development and will maximise critical partnerships with both industry and philanthropists.

The commitment from The National Brain Appeal will support three key facilities:

#### Stem Cell Facility

This pioneering facility will enable researchers to study diseases in a petri dish using stem cells taken from skin biopsies. These cells can then be used to speed up the development and testing of new treatments and therapies for patients. The facility will be led by Professor Rickie Patani and Professor Selina Wray.



Stem cell models have revolutionised the way we model diseases in the lab, allowing us to create patient-specific 'disease in a dish' models. This approach will increase the likelihood of lab findings translating into clinical benefit, which is the core aim of everything we do.

Professor Selina Wray



#### Patient Research Hub

A dedicated hub promoting patient-oriented research from their first clinic appointment onwards. Ongoing research will be widely publicised to those coming to clinics, and patients will be encouraged and enabled to take part in projects with facilities for detailed explanation of what is involved and for the necessary tests to be done. Research ambassadors will be on hand to answer questions on trials and encourage outpatients' enrolment in research projects in a welcoming and informative setting.



The co-location of clinical activity with research laboratories will ensure that researchers appreciate the key issues facing patients and will be highly motivating for research teams, and inspiring for patients who will understand the work being done to alleviate their situation. The clinical research hub will allow the numbers of individuals who take part in research to be increased tenfold and the proximity of research laboratories to the clinic will enable rapid translation of new advances into clinical use.

Professor John Duncan



#### MRI Scanning Unit

This suite of six MRI scanners (of which The National Brain Appeal will fund two) – in addition to those already operating at NHNN – will create one of the largest research-focused neuroradiology scanning facilities in the world.

The scanners will be optimised and run so that patients will only have to attend one appointment for their clinical and research scan, greatly improving the efficacy and ease of the patient experience.

## Centre for Rare Dementia Support

(Funding area: Neurodegeneration)

Unusual and young-onset dementias are under-researched, under-recognised and under-supported. Of the 1m people in the UK expected to experience dementia by 2025 between 5%-20% will experience an atypical, young-onset or rare dementia with symptoms often emerging before they turn fifty. 'Rare' dementias are devastating, isolating, and increasingly common. The seven conditions currently supported by Rare Dementia Support (RDS) are frontotemporal dementia (FTD), primary progressive aphasia (PPA), posterior cortical atrophy (PCA), familial Alzheimer's disease (FAD), familial FTD, Lewy body dementia (LBD) and Young-Onset Alzheimer's Disease. Everybody with a rare dementia has exceptional needs that are not currently reflected in society's understanding of the condition.

The National Brain Appeal has supported Rare Dementia Support (RDS) since the first meetings were established in 1994 and this year committed £300,000 to develop and extend the services. These include regular, specialist support groups, in London and regionally, as well as newsletters, contact networks and an online forum for people living with, or affected by, a diagnosis of a rarer dementia.

As part of this a new, dedicated RDS website – raredementiasupport.org – was launched on 29 February 2020. In response to the pandemic and the massive increase in support calls, 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 were 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.



RDS support is priceless at this time.

I love when there's that burst of banter and laughter, and you know what the greatest thing and feeling is? No one is judging you: you are you, dementia, warts and all.

This group is an important part of things for me... I reflect on it sometimes weeks in the past or into the future, and it's like the oxygen of shared experience, it's sort of validating, it means that I'm not alone, however rough it feels.

RDS Members' Feedback

The Trustees have now pledged to raise up to £7million to create the world's first centre of excellence for supporting those living with inherited, atypical, and young-onset dementias. The Rare Dementia Support Centre will exemplify how best to support those living with a rare dementia, through the involvement of its members and visitors in research and will lead in the bespoke education of families, healthcare and other relevant professionals. The Centre will also pioneer research into the impact of support services on people living with a rare dementia: both for those with a diagnosis, their carers and families.

RDS aims to meet the Dementia Challenge 2020 objective of 'Every person diagnosed with dementia having meaningful care... which supports them and those around them' (Department of Health, 2019)

University College London's (UCL) Dementia Research Centre in Queen Square is a world-leading centre for expertise in rare, inherited and young-onset dementias. With 20 years' expertise of running support groups, and over 2,000 people registered as members of Rare Dementia Support, it is essential that the first Centre of excellence dedicated to rare dementias be closely integrated with the clinical and research expertise of UCL's Dementia Research Centre at Queen Square, London and the UK Dementia Research Institute.

#### **Brain Cancer**

(Funding areas: Queen Square, Neurosurgery, Technology & Innovation)

The National Brain Appeal has had a significant impact on brain cancer care over the last ten years and more. The charity provided the critical initial funding to establish the first specialist brain cancer team, the Brain Tumour Unit, bringing together specialist doctors, surgeons, nurses, therapists and researchers — a critical mass of expertise and experience — and the UK's first dedicated ward for brain tumour patients — the Molly Lane Fox Unit, both at The National Hospital for Neurology and Neurosurgery. This funded doctors, nurses and research roles to enhance the patient experience and develop research. To advance brain cancer surgery, we funded the UK's first interventional MRI scanner, where intraoperative scanning allows for greater precision and more effective surgery.

We are currently funding three research projects to develop new surgical instruments and techniques, to determine brain tumour boundaries with novel intraoperative microscopy techniques, and to develop biological image-guided adaptive radiotherapy, all with the goal of reducing the size of tumour remaining after treatment without inflicting other damage). These developments, alongside Dr Mulholland's clinical trials outlined below, have helped establish The National Hospital as a world-leading centre for brain cancer.



The Brain Tumour Unit simply would not exist as it does today without The National Brain Appeal. They have given us so much support over the years to help us function at such a high level and provide the very best care for our patients.

It is so important to have the right environment and support for patients who have been diagnosed with a brain tumour. The Molly Lane Fox Unit offers that not only in a physical sense as a ward but it also provides a focus for clinical staff, a concentration of expertise among the professional groups. It is much more than just where we treat our patients. It allows us to provide good, cohesive care and we are very grateful to The National Brain Appeal for making this happen.

Dr Naomi Fersht, consultant clinical oncologist at UCLH and lead clinician for Brain Tumour Unit



In my 26 years as a consultant I've lost count of the number of times The National Brain Appeal has supported neurosurgical projects. Thanks to the charity we had the first interventional MRI scanner in the UK, the first dedicated ward for brain tumour patients and a new state-of-the-art operating theatres suite. The support of the charity enables us to have the best equipment and the best environment to innovate above and beyond being supported by the NHS.

Mr Neil Kitchen, consultant neurosurgeon at The National Hospital and lead neurosurgeon for neuro-oncology, speaking about how The National Brain Appeal has helped advance surgery for patients with brain cancer

The National Brain Appeal has also funded the UK's first large-scale, charitably funded, immunotherapy clinical trial for NHS patients recently diagnosed with glioblastoma brain cancer. 119 people were recruited to the IPI-GLIO trial in just over two years — this is the biggest number of UK patients ever recruited to a brain cancer clinical trial. This £295k funding enabled the trial to take place in seven centres around the UK, in Cambridge, Edinburgh, London (UCLH and Guy's Hospital), Manchester, Middlesex and Oxford.

Glioblastoma is the most common type of primary, malignant and very aggressive brain tumour with around 2,200 cases diagnosed each year in England (and around 3,200 across the UK). The average survival time is around 15 months, with fewer than 10 per cent of patients alive five years after diagnosis following standard treatment.

Dr Paul Mulholland, consultant medical oncologist at UCLH, designed the phase II clinical trial and is the lead investigator. It is sponsored and managed by the University of Oxford. The pharmaceutical company Bristol Myers Squibb also contributed to part funding the study and provided the drug ipilimumab.

The National Hospital for Neurology and Neurosurgery, UCLH and DRC Specialist Cognitive Disorders Clinic are located in Queen Square. The plan is for the new Centre to be no more than a few minutes' walk away - allowing patients to attend clinical appointments and then make use of the support centre immediately afterwards. The Centre will act as a hub for RDS' regional network of 27 support groups, providing advice, training and resources to the group facilitators of those groups. Over 70% of current online traffic to the RDS website is from outside the UK, showing how unique this global resource is and how necessary. Such is the rarity of information, treatment and support outside Britain that members will travel from other countries to attend support groups, making London an operationally effective place to site the Centre.

It will provide an exceptional, bespoke space for people living with rare dementias and their families that will:

- Offer holistic support, guidance, education and empowerment.
- Inspire and pioneer research into the impact of support services. The research will challenge public perceptions by communicating the experience and biology of the dementias.
- Lead in the bespoke education and training of families, healthcare and other professionals (such as speech therapists, nurses, physiotherapists, opticians and GPs) who work with people living with rare dementias.
- Create an in-person and online community of integrated professional and peer-to-peer support and advice.

The education, training and research undertaken at the Centre will also benefit those in clinical roles; those who work with and rely on people living with a rare dementia for their research; those who research the way care and support is offered to those with a diagnosis and other professionals, practitioners and students who support and work with people with a rare dementia.

The new Centre will create spaces that are light and welcoming, informal and comfortable, conveying a sense of calm and warmth. Seating, equipment and signage will be designed for and by people with a range of needs. The design, layout, lighting, acoustics and decor will reflect best practice and world-leading research in terms of disability and dementia-friendly access and use. Flexible space will be available to host intimate, themed group discussions for 10-20 people, while also being adaptable for larger groups and events. Smaller support rooms will offer space for conversations with individuals, couples and families with speech and language therapists, psychologists, counsellors and our legal advice team. There will be pods and booths for sharing information, IT and other resources, and for phone consultations and webinars. These facilities will be complemented by a space for physical, artistic and cultural activities, and assorted desk space for members of the RDS team. Audio-visual equipment enabling recording and live-streaming will increase the reach and impact of the educational, training and support work. It is also planned that an outside space or garden would be created for members' wellbeing.

Following standard treatment for glioblastoma of surgery (where appropriate), radiotherapy and chemotherapy, patients recruited to the trial were given ipilimumab, a drug that has seen significant improvements in survival rates for people with melanoma skin cancer. The patients will be followed up over the next 18 months and the findings will be presented to the American Society of Clinical Oncology in May 2023.

Now that we have fully recruited to the IPI-GLIO trial we have planned a programme of trials so this work can continue. We have established a Glioblastoma Research Group and laboratory at UCL Cancer Institute. We are bringing together the newest drugs from the pharmaceutical industry together with the latest developments in scientific research to try to find a cure for this devastating disease.

Dr Paul Mulholland, consultant medical oncologist at UCLH, looks beyond this trial

Brain cancer is a deadly and devastating disease. The National Brain Appeal is proud to have supported Dr Paul Mulholland's work and funded this significant immunotherapy clinical trial. This builds on more than ten years of investment by the charity, establishing the dedicated Brain Tumour Unit, dedicated ward and state-of-the-art equipment to help improve the diagnosis and treatment of brain cancer.

Theresa Dauncey, chief executive of The National Brain Appeal

#### The Small Acorns Fund

(Funding area: Queen Square)

Thanks to our Small Acorns Fund we have managed to make a difference to so many patients. More than 100 projects have been funded since we started seven years ago.

This grant scheme is open to front-line staff at The National Hospital and the UCL Queen Square Institute of Neurology, giving them the opportunity to apply for funding to fast-track smaller scale projects that are outside the scope of NHS funding, but will have a big impact and benefit for patients.

Grants range from £500-£5,000 (with one grant of £10,000 being awarded to an exceptional project). Our aim is to raise £40,000 per year to be able to continue funding such projects. In this financial year, more than 15 projects were agreed at a total cost of £48,000. The projects supported are wide-ranging and provide a fantastic opportunity to introduce new activities which have a positive impact on patients.



One project successfully completed this year was to fund a biocompatible 3D printing lab to enable the use of 3D models for pre-operative planning and training, pre-op simulation, and research. It is now a critical tool for improving informed consent during video clinic consultations.



I'm always very impressed by the projects. A great plus of the Fund, as far as we are concerned, is that the projects are proposed by people at the 'sharp end' and that our donations go in their entirety towards developing those projects.

Anton Shellim, Trustee, The A B David Charity

## Motor Neuron Disease (MND) Clinical Lead

(Funding area: Neurodegeneration)

MND is a rapidly progressing and fatal disease that affects the brain and spinal cord. It affects up to 5,000 adults in the UK at any one time and every day in this country six people are diagnosed with the disease and a further six people die from it. The development of a world-leading and collaborative clinical and research unit for patients with MND at Queen Square highlighted the urgent need to create a new role — Clinical Academic Lead in MND — to drive both research trials and clinical service provision at Queen Square and throughout the UK. The National Brain Appeal provided £144,000 to support this post for the first two years.

#### Mitochondrial Diseases

(Funding area: Neurology)

The charity recently fully funded a biomedical translational scientist position. Dr Padraig Flannery is now in post and working on a new collaborative Queen Square service to support patients affected by mitochondrial disorders. Every 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

The service – which brings together both clinical genetics and functional biochemistry – will provide bespoke diagnostic functional tests and give insights into the effect of DNA variants on mitochondrial function and their impact on patient health. For patients, this will mean that the team will be in a much stronger position to provide a definitive diagnosis and able to develop better targeted treatments. The National Brain Appeal has committed £60,000 from designated funds.

#### 'Smart' shunt for hydrocephalus

(Funding area: Neurosurgery)

About one in 1,000 newborns develop hydrocephalus and most will be shunt dependent for life. Currently, 40% of shunts fail within two years and 98% fail within 10. From this joint research project between hydrocephalus neurosurgeons at Queen Square and the whole-body sensorimotor lab at UCL, the aim is to provide the knowledge necessary to develop an algorithm to design implanatable 'smart shunts' for hydrocephalus patients – in order to accurately measure and understand the exact timing of over or underdrainage. The charity has provided nearly £60,000 funding to create a research associate post to support this study and to undertake collection, storage and analyses of the data.

# Covid-19, Infectious and Autoimmune Encephalitis Service

(Funding area: Neurology)

The National Brain Appeal provided almost £65,000 towards a new, consultant-led service (Dr Manji, Dr Zandi and Dr McNamara) to assess patients presenting with neurological complications of Covid-19. A clinic opened in November 2020 to respond to increasingly urgent requests from doctors faced with growing number of patients with neurological complications (such as headache, "brain fog", muscle pain and fatigue) after contracting the virus. In addition, the funding 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 increased number of patients.



# The National Brain Appeal Aphasia Service (Funding area: Neurology)

The National Brain Appeal has committed to raise £600,000 to support this transformative high dose therapy programme for stroke and brain injured patients with aphasia. The Intensive Aphasia Programme (ICAP) was paused due to Covid but it is planned to restart in late summer 2021. The model has been amended to a four-day-a-week over four weeks model, so it remains high-dose but less fatiguing for the patients and their families. The team is working with the NHNN management team to apply for Specialised Commissioning with the local CCG group. They also intend to publish the analysis of the patients' goals data in a peer-reviewed specialist speech and language therapy journal.

#### Kennedy's Disease (KD)

(Funding area: Neurodegeneration)

Kennedy's Disease, or X-linked Motor Neuron Disease, is a rare, inherited neuromuscular disorder. 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. The disease is caused by a genetic mutation of a specific gene on the 'X' (female) chromosome. Because it is relatively rare, Kennedy's Disease is often initially misdiagnosed or goes undiagnosed for years. There is no cure at present but a number of novel treatments are being trialled globally. The KD Clinic at The National Hospital is the only one dedicated to this disease in the UK. More than 80 patients are seen each year and the service aims to offer specialist expertise and focus on finding effective treatments that may improve symptoms and stop progression. The National Brain Appeal – thanks to a very generous anonymous donor - has been able to fund a consultant neurologist post within the Clinic for three years.

#### **Innovation Fund**

(Funding area: Neurology)

The Innovation Fund supports the most novel ideas, enabling new ways to diagnose patients and identify new treatments, drugs and technologies.

One of the major problems faced by clinicians and researchers is the lack of initial funding to get pioneering ideas off the ground quickly. The Innovation Fund supports this 'bench to bedside' process, so that clear progress can be achieved, by awarding grants of between £50,000 and £150,000. Details of four recently awarded grants are set out below.



# Improving the diagnosis, prognosis and treatment of neuro conditions

Consultant neurologist, Professor Michael Lunn was awarded an Innovation Fund grant in August 2020 for his work in improving the diagnosis, prognosis and treatment of many neuromuscular, neurodegenerative and inflammatory neurological disorders.

In many neurological diseases cell damage or decay releases tiny amounts of molecules into surrounding fluids. Some of these molecules are specific to the disease (huntingtin in Huntington's Disease or amyloid proteins in Alzheimer's disease) and some represent more general damage to cells (for example a molecule called neurofilament in multiple sclerosis (MS) or inflammatory neuropathies). These molecules are some of many disease markers called 'fluid biomarkers'.

Accurate diagnosis, prognosis and getting the treatment right for many neurological conditions depends on detecting measurable 'disease characteristic' biomarkers in body fluids such as blood or spinal fluid. However, the amounts released are often too tiny to measure using standard laboratory techniques.

This grant has been used to purchase a machine called a SiMoA (Single Molecule Analyser) for the NICL (Neuroimmunology and CSF Laboratory) based in Queen Square where tens of thousands of clinical assays — medical investigations — take place every year.

The sensitivity of this machine means that biomarkers found in the cerebrospinal fluid in higher amounts can be measured in much lower amounts in the blood, avoiding the need for lumbar punctures, which can be painful, time-consuming and distressing for patients.



This ultrasensitive machine can detect levels of biomarkers equivalent to dissolving a teaspoon of sugar in an Olympic swimming pool. Patients will benefit from a far greater accuracy of prognosis, and treatment plans for conditions including CIDP, MS, dementia and inflammatory peripheral neuropathies. For patients receiving IVIG it will help tailor their therapy, and assess when and which treatment is necessary.

Professor Michael Lunn

The SiMoA also means many more patients can be assessed more quickly with less risk and at far less cost to the NHS. The SiMoA can test up to 32 patients a day and can 'read' a sample in just 45 minutes.

The SiMoA also allows the laboratory to discover new blood or spinal fluid biomarkers that to date have been at levels too small to measure. The NICL has recently identified two new useful molecules that can detect damage levels in peripheral nerves and in the cells of the peripheral nervous system that make myelin (Schwann cells) that can be damaged in peripheral neuropathies. NICL can develop this test further for clinical use to help doctors follow damage and treatment effects in peripheral neuropathies.

These new tests will be available nationally once established at The National Hospital.

#### How does climate change affect your brain?

Global warming is happening now. It affects everyone, but people with a neurological condition are less resilient and rising temperatures will affect them more than others over the coming years. We are delighted to announce that a fourth Innovation Fund grant of £55,000 has been awarded to Professor Sanjay Sisodiya to investigate and mitigate the harmful effects of these changes on people affected by neurological conditions. This project aims to pioneer ways to help patients adapt and thrive despite increasing temperatures, 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 the issue is now one of their strategic priorities. There are three main areas of focus for this project:

- A series of surveys will be conducted by The National Hospital (and in collaboration with diseasespecific charities) to identify which groups of people will be most at risk of worsening symptoms or disease progression linked to global warming. This will give patients immediate, short-term coping strategies for inevitable heatwaves and also provide vital data for future studies.
- The project will also look at genetic susceptibility to extreme heat in a range of neurological conditions. Contributing to NHS target of being net-zero by 2040 the challenge of reducing the carbon footprint of Queen Square will also be addressed starting with The UCL Institute of Neurology (IoN). The use of virtual clinics will be explored to avoid unnecessary travel and patients waiting in over-heated clinics. The aim is to reduce the IoN's carbon footprint by at least 5% over the year. This project will play a crucial part in establishing new collaborations in Queen Square to address this challenge.
- The team will determine whether spiking temperatures might affect neurological drugs and so provide additional advice about storage at home and in hospitals.

There are no boundaries to global warming, 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. Global warming – a greater challenge – demands even more. The Innovation Fund is delighted to fund this vital work and help Queen Square to lead the way.

# Piloting a new 'pre-ambulance' remote assessment for stroke patients

This study aims to pilot the use of pre-ambulance remote video assessment/ triage for patients with possible stroke. Every year in the UK 100,000 people have strokes and hyperacute treatments can dramatically improve outcomes. Timing in the first minutes is critical and specialist assessment soon after onset could increase access to treatment, deliver faster treatment and provide better care for non-stroke cases. This pilot study will be a collaboration between The National Hospital, London Ambulance Service (LAS) and NHS 111 First service and, if successful, would lead to an NHS-wide roll-out of the scheme.

# A new tool to improve diagnosis in hereditary neurodegenerative diseases

Neurogenetic disorders are frequent neurological conditions affecting at least 1 in 423 people in UK. More than 40 neurogenetic diseases are caused by complex DNA defects called repeat expansion and structural variants. For these diseases, the current diagnostic approach is inaccurate and laborious. Genome optical mapping (GOM) is a new technology that can overcome current limitations. However, further data is needed to support its use in clinical practice.

Enrico Bugiardini aims to assess whether GOM can improve the diagnostic process of common neurogenetic diseases such as Facioscapulohumeral muscular dystrophy; Cerebellar-Ataxia, Neuropathy, Vestibular-Areflexia (CANVAS); familial cases of amyotrophic lateral sclerosis and frontotemporal dementia.

# Integrating Virtual Reality into multidisciplinary medical education at Queen Square

(Funding area: Education and Staff Development)

A new project has been approved looking at how to use Virtual Reality technology for simulation activities to improve training for clinical staff in a safe and less pressured environment.

Simulation is an immersive experience where the learner is exposed to certain tasks and skills in a non-confrontational blame-free environment allowing them to flourish. It is an excellent tool in conjunction with structured learning and can enhance understanding. The newer generation of healthcare professionals prefer more of an interactive and immersive form of technology that is easily replicated and can help make choices and apply the information immediately using software. This is known as Virtual Reality (VR).

This kind of interactive gaming-based education could help in improving critical thinking and clinical reasoning. Traditionally emphasis has been based on knowledge and its application without any emphasis laid on non-technical skills. Virtual reality is more helpful in improving cognitive skills, attitude and team work. It's reproducibility is limitless. VR offers benefits for learners and educators, delivering cost-effective, repeatable, standardising clinical training on demand.

With funding for the equipment from The National Brain Appeal, the intention is to set up a pilot dedicated VR area to introduce this novel way of delivering education to junior members of staff working on the wards where there is a time critical nature to identify and treat acutely unwell deteriorating patients. The aim is to teach healthcare professionals the importance of non-technical skills, laying the emphasis on cognition, attitudes and situational awareness and its impact on well-being, sense of responsibility and ultimately safeguarding patient care to a high standard.

#### **Donors**

Without the support of so many donors, alongside a number of companies and grant-making trusts and foundations. The National Brain Appeal would be unable to fund such a wide range of projects. Our grateful thanks to all who have supported this year.

These include:

#### A Letter in Mind

The Foyle Foundation

#### **Education and Staff Development**

Bryan Guinness Charitable Trust

#### **Emergency Fund**

The Danny Sullivan Group Zendium

#### General/Queen Square

Aylesfield Foundation
Basil Samuel Charitable Trust
Cecil Rosen Foundation
G L Doubleday Charitable Trust
Joseph Strong Frazer Trust
Lord Barnby's Foundation
Lund Trust, a charitable fund of
Lisbet Rausing and Peter Baldwin
WRA Charitable Trust
Oldhurst Trust
Philip and Psiche Hughes Trust
Rest-Harrow Trust
The Kariya Family Trust
Three T Charity
Toye Charitable Trust

#### **Immunotherapy**

Ambrose & Ann Appelbe Trust Dromintee Trust Q Charitable Trust

#### Innovation Fund

C A Pilgrim 3 Consuelo and Anthony Brooke Charitable Trust James Weir Foundation

#### Neurorehabilitation

SameYou

#### Neurosurgery

The Stella Foundation

# Rare Dementia Support and Rare Dementia Support Centre

Barclays 100x100 UK COVID-19
Community Relief Fund
Dementia Services Development Trust –
Disruption Award
Girdlers' Company Charitable Trust
Lindt & Sprüngli (UK)
Mercer's Charitable Foundation
October 09 Charitable Trust
Rosetrees Trust
Selfridges Group Foundation

#### Small Acorns Fund

A.B. David Charity

#### Reserves and risk

#### Reserves policy

Total reserves held at the year end by the Charity amounted to £7,788,598 (2020: £5,790,693), of which £3,738,731 were held as restricted funds (2020: £3,186,583) and a further £2,650,833 were designated for specific purposes (2020: £2,089,428)

The Trustees have established a policy whereby the unrestricted funds not committed or invested in tangible fixed assets ("the free reserves") held by the Charity should be sufficient to meet between 9 and 15 months staff and office costs. Therefore, the target for free reserves is between £1,032,105 and £1,720,175.

Total free reserves as at 31 March 2020 were £1,399,034. The Trustees consider that they would be able to continue the current activities of the Charity in the event of a drop in funding as a sufficient proportion of the designated funds will not be required in the next 12 months.

#### Risk exposure

The Trustees have addressed the major risks to which the Charity is exposed, in particular, those relating to its operations and finances, and are satisfied that the systems in place are sufficient to manage the exposures identified. As the Charity does not directly provide charitable services the main risks are being unable to deliver promised funding on time. However, Trustees are careful not to overcommit and pledges are considered in relation to assets held and predicted cash flow. The risk register was reviewed in September 2020.

#### **Trustees**

The Trustees of the Foundation who served during the year were:

Jackie Ashley (Chair)

(appointed 14 May 2020)

Richard Blakey

(appointed 9 February 2021)

Caroline Church

Edward Datnow

(resigned 9 July 2020)

Joanna David

Professor John Duncan

**Jules Foster** 

(appointed 15 October 2020)

Joan Grieve

Professor Mike Hanna

James Knight

(appointed 15 October 2020)

Elizabeth Kornat

Herchel Maclear-Jordan

(resigned 15 October 2020)

Suzanne Millar

(appointed 15 October 2020)

Diarmid Ogilvy (Treasurer)

Michael Powell

Michael Smith

**Professor Alan Thompson** 

Dr Chris Turner

The President of the Foundation is **Edward Datnow FRCS** (appointed 15 Oct 2020)

Key management personnel remuneration is charged directly from University College London Hospitals NHS Foundation Trust who determine the salary rates.

#### Statement of Trustees' Responsibilities

The Trustees (who are also directors of The National Hospital for Neurology and Neurosurgery Development Foundation for the purposes of company law) are responsible for preparing the Trustees' Report (incorporating the Directors' Report) and the financial statements in accordance with applicable law and regulations.

Company law requires the Trustees to prepare financial statements for each financial year. Under that law the Trustees have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the income and expenditure of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and apply them consistently
- observe the methods and principles in the Charities SORP
- make judgments and estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware; and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislations in other jurisdictions.

#### **Auditor**

A resolution to re-appoint the auditor, Moore Kingston Smith LLP will be proposed at the annual general meeting.

#### Small company provisions

The report has been prepared in accordance with the special provisions for small companies under Part 15 of the Companies Act 2006.

By order of the Trustees

J. Ashley

**Jackie Ashley** 

Chair

Date: 10/07/21

# Independent Auditor's Report

# Independent Auditor's Report

#### **Opinion**

We have audited the financial statements of the National Hospital for Neurology and Neurosurgery Development Foundation ('the company') for the year ended 31 March 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 'The Financial Reporting Standard Applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs(UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least 12 months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

#### Other information

The other information comprises the information included in the Annual Report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

# Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Annual Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Annual Report has been prepared in accordance with applicable legal requirements.

# Matters on which we are required to report by exception

In the light of the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption in preparing the Trustees' Annual Report and from preparing a Strategic Report.

#### Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

# Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

# Explanation as to what extent the audit was considered capable of detecting irregularities, including fraud

The objectives of our audit in respect of fraud, are; to identify and assess the risks of material misstatement of the financial statements due to fraud; to obtain sufficient appropriate audit evidence regarding the assessed risks of material misstatement due to fraud, through designing and implementing appropriate responses to those assessed risks; and to respond appropriately to instances of fraud or suspected fraud identified during the audit. However, the primary responsibility for the prevention and detection of fraud rests with both management and those charged with governance of the charitable company.

Our approach was as follows:

— We obtained an understanding of the legal and regulatory requirements applicable to the charitable company and considered that the most significant are the Companies Act 2006, the Charities Act 2011, the Charity SORP, and UK financial reporting standards as issued by the Financial Reporting Council.

- We obtained an understanding of how the charitable company complies with these requirements by discussions with management and those charged with governance.
- We assessed the risk of material misstatement of the financial statements, including the risk of material misstatement due to fraud and how it might occur, by holding discussions with management and those charged with governance.
- We inquired of management and those charged with governance as to any known instances of noncompliance or suspected non-compliance with laws and regulations.
- Based on this understanding, we designed specific appropriate audit procedures to identify instances of non-compliance with laws and regulations. This included making enquiries of management and those charged with governance and obtaining additional corroborative evidence as required.

As part of an audit in accordance with ISAs (UK) we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purposes of expressing an opinion on the effectiveness of the charitable company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees.

- Conclude on the appropriateness of the Trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

#### Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to any party other than the charitable company and charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Moore Krigston Jak LLP

#### Neil Finlayson

(Senior Statutory Auditor)
for and on behalf of Moore Kingston Smith LLP,
Statutory Auditor: Devonshire House, 60 Goswell Road
London, FC1M 7AD

Date: 15/10/21

# Financial statements

# **Statement of Financial Activities**

		Unrestricted funds	Restricted funds	Total funds 2021	Total funds 2020
lnaama	Notes	£	£	£	£
Income					
Donations and legacies	4	1,807,698	1,317,328	3,125,026	1,763,825
Investment income	5	255,179	-	255,179	255,831
Rental income		55,339	-	55,339	51,442
Total income		2,118,216	1,317,328	3,435,544	2,071,098
Expenditure					
Costs of raising funds	6	639,840	-	639,840	568,489
Expenditure on charitable activities	7	887,585	942,189	1,829,774	1,334,476
Total expenditure		1,527,425	942,189	2,469,614	1,902,965
Net income before transfers	8	590,791	375,139	965,930	168,133
Transfers between funds		(177,029)	177,029	=	-
Net income before gains and losses		413,762	552,168	965,930	168,133
Realised gains (losses) on revaluation of investments					
Unrealised gains (losses) on revaluation of investments	11	1,031,975	-	1,031,975	(652,801)
Net income/(expenditure) and net movement in funds		1,445,737	552,168	1,997,905	(484,668)
Reconciliation of funds				-	-
Total funds brought forward at 1 April 2020		2,604,130	3,186,563	5,790,693	6,275,361
Total funds carried forward at 31 March 2021		4,049,867	3,738,731	7,788,598	5,790,693

All above amounts are derived from continuing operations.

All gains and losses for the year are shown above.

The notes on pages 29 to 38 form part of these financial statements.

The National Hospital for Neurology and Neurosurgery Development Foundation

# **Balance Sheet**

	Notes	£	2021 £	٤	2020 £
FIXED ASSETS					
Investments	11		7,566,717		5,798,324
			7,566,717		5,798,324
CURRENT ASSETS					
Debtors Bank balances and cash in hand	12	129,281 648,020		344,231 179,390	
		777,301		523,621	
CREDITORS					
Amounts falling due within one year	13	(555,420)		(531,252)	
NET CURRENT ASSETS			221,881		(7,631)
TOTAL ASSETS LESS CURRENT LIABILITIES			7,788,598		5,790,693
ACCUMULATED FUNDS					
Unrestricted funds					
General fund Designated funds	14 14		1,399,034 2,650,833		514,702 2,089,428
Total Unrestricted Funds			4,049,867		2,604,130
Restricted Funds	15		3,738,731		3,186,563
TOTAL FUNDS	16		7,788,598		5,790,693

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were authorised for issue on 07/10/21 and were signed on their behalf by

Diarmid Ogilvy

Treasurer

Jackie Ashley

J. Ashley

Chair

Company number 01844281

The National Hospital for Neurology and Neurosurgery Development Foundation

# Statement of Cash Flows

A. RECONCILIATION OF NET INCOMING RESOURCES
TO NET CASH INFLOW FROM OPERATING ACTIVITIES

TO NET CASH INFLOW FROM OPERATING ACTIVITIES		2021	2020
Net movement in funds		1,997,905	(484,668)
(Gain)/Loss on disposal of fixed assets/investments (unrealised)		(1,031,975)	652,801
(Gain)/Loss on disposal of fixed assets/investments (realised		- 214,950	- (1 0 E 0 O E)
Decrease/(increase) in debtors Increase/(decrease) in creditors		214,950	(185,805) (336,253)
Investment (income) shown in investing activities		(255,179)	(255,831)
investment (income) shown in investing dedivides		(233,173)	(233,031)
Net cash inflow from operating activities		949,869	(609,756)
STATEMENT OF CASH FLOWS	Note	2021 £	2020 £
Net cash inflow from operating activities	А	949,869	(609,756)
Cash flows from investing activities			
Financial investment (purchase)		(500,000)	=
Proceeds from disposal of investments (at opening market value)		-	-
Gain/(loss) on sale of investments (realised)		=	-
Investment income received		255,179	255,831
(Increase)/decrease in investment cash		(236,418)	(6,732)
Cash (used in)/provided by investing activities		(481,239)	249,099
(Decrease)/increase in cash and cash equivalents in the year		468,630	(360,656)
Cash and cash equivalents at the beginning of the year		179,390	540,046
Cash and cash equivalents at the end of the year		648,020	179,390

### Notes to the financial statements

#### 1. Company information

The National Hospital for Neurology and Neurosurgery Development Foundation is a charitable company limited by guarantee incorporated in England & Wales and domiciled in England.

The Registered Office is The National Hospital, Queen Square, London, WC1N 3BG.

The principal activity of the Charity is to promote the relief and prevention of diseases of the nervous system.

The Company's registered number is 01844281. The registered Charity number is 290173.

The functional and presentation currency of these financial statements is GBP and the financial statements are rounded to the nearest £1

#### 2. Accounting policies

#### (a) Accounting basis

The financial statements cover the period 1 April 2020 to 31 March 2021.

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities COR (FRS 102)), the Financial Reporting standards applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

The National Brain Appeal meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant policy note(s).

They are prepared under the historical cost convention with the exception of fixed asset investments, which are recorded at market value.

#### (b) Going concern

The financial statements are prepared on a going concern basis which assumes the charitable company will continue in operational existence for the foreseeable future.

The Trustees have considered the going concern status of the Charity for a period of twelve months from the date of approval of these financial statements, and have specifically looked at the impact of Covid-19. A review of the budget and cash flow was undertaken and due to a large number of legacy notifications and a successful year in most areas of fundraising, the Trustees feel confident that the Charity has the resources to meet its commitments. It has been possible to continue funding all projects that have not been delayed or altered and sufficient funds are held to support all projects currently underway.

The Trustees do not believe there are any indicators why the going concern status of the Charity would not be supported and this is supported by the open market investments of £7,054,463 (2020: £5,798,324) and total funds of £7,788,598 (2020: £5,790,693). Outflows from the Charity are dependent on the income levels received by the Charity on an on-going basis.

Accordingly, the Trustees continue to adopt the going concern basis in the preparation of the financial statements.

#### (c) Incoming resources

All incoming resources are included in the Statement of Financial Activities when the Charity is legally entitled to the income and the amount can be quantified with reasonable certainty

#### (d) Legacies

Legacies are included when the Charity is advised by the personal representative of an estate that payments will be made, is probable of its receipt, and the amount involved can be quantified.

#### (e) Incoming resources from activities to generate funds

Income from activities to generate funds comprises amounts receivable from fundraising events for which tickets have been sold.

#### (f) Resources expended

All expenditure is accounted for on an accruals basis, inclusive of irrecoverable VAT, and is allocated to the appropriate heading in the accounts.

Costs of raising funds include the costs incurred in generating voluntary income and the costs of direct publicity intended to raise the profile of the Charity.

Charitable expenditure comprises services supplied and activities undertaken which are identifiable as wholly or mainly in support of the Charity's objectives.

Governance costs included in charitable activities are those costs associated with the governance arrangements of the Charity, and these include audit, legal advice for Trustees, costs associated with Trustee meetings and the cost of the preparation of the statutory accounts.

Support costs are those costs which enable raising funds and charitable activities to be undertaken. Where activities are incurred relate to more than one cost category, it is apportioned on the most appropriate basis, predominantly with reference to staff time, and on a reasonable and consistent basis.

#### (g) Investments

Investments are accounted for at market value, which gives rise to unrealised gains/losses which are included in the Statement of Financial Activities. Realised gains/losses arising on the disposal of investments during the year are also included in the Statement of Financial Activities.

#### (h) Funds

The General fund is available to use at the discretion of Trustees in furtherance of the Charity's objectives. Designated funds comprise funds which have been set aside by the Trustees for specific purposes. Restricted funds are funds received which are subject to specific restrictions as imposed by the donor or the nature of the appeal.

#### (i) Cash and cash equivalents

Cash is represented by cash in hand and deposits with financial institutions repayable without penalty on notice of not more than 24 hours. Cash equivalents are highly liquid investments that mature in no more that three months from the date of acquisition and that are readily convertible to known amounts of cash with insignificant risk of changes in fair value.

#### (j) Operating leases

Operating lease charges are recognised in the Income and Expenditure Account when due.

#### 3 Judgements in applying accounting policies and key sources of estimation uncertainty

In preparing the Financial Statements, management is required to make estimates and assumptions which affect reported income, expenses, assets, liabilities and disclosure of contingent assets and liabilities. Use of available information and application of judgement are inherent in the formation of estimates, together with expectations of future events are believed to be reasonable under the circumstances. Actual results in the future could differ from such estimates.

#### 4 Donations and legacies

J	Unrestricted	Restricted	2021	2020
General donations	392,652	659,594	1,052,246	620,905
Donations from charitable trusts	74,055	524,468	598,523	234,702
Legacies	1,192,005	39,468	1,231,473	262,246
Sporting and challenge events	50,033	34,676	84,709	345,862
Special events & activities	98,953	59,122	158,075	300,110
	1,807,698	1,317,328	3,125,026	1,763,825

#### 5. Income from investments

				2021	2020
	Interest receivable from bank deposit accounts			23	90
	Income from investment portfolio			255,156	255,741
_				255,179	255,831
6.	Raising funds				
	Direct costs			251,333	198,911
	Supposit sects (note 9)				
	Support costs (note 8) Advertising			0	40.741
	Staff costs			265,898	217,943
	Rent & rates			86,873	80,280
	Other costs			35,736	30,614
				639,840	568,489
7	Charitable activities				
,	Charitable activities	Unrestricted	Restricted	2021	2020
	Direct costs	505,885	942,189	1,448,074	985,458
	Governance costs (note 7a)	90,255		90,255	60,616
	Support costs (note 8)				
	Staff costs	210,865		210,865	169,709
	Rent & rates Other costs	29,781 50,799		29,781 50,799	27,110 91,583
_		887,585	942,189	1,829,774	1,334,476
_				, , , , , , , ,	
	Grants by activity			2021	
	Neurodegeneration			360,809	
	Neurology			73,193	
	Neurosurgery			431,078	
	Queen Square			81,335 236,663	
_	Technology & Innovation				
_				1,183,078	
	Grants by organisation				
	UCLH NHS Foundation Trust			660,643	
	University College London			312,628	
	University of Oxford			128,333	
	Other			81,474	
				1,183,078	

No grants were made to individuals in the current or prior year.

#### 7a Governance costs

		2021	2020
St	staff costs	32,461	34,431
Re	Rent & rates	3,309	3,012
A	Audit fee	14,541	11,940
Ins	nsurance	814	990
0	Other costs	39,130	10,243
		90,255	60,616
8 Su	Support costs		
		2021	2020
Re	Rent and rates	116.654	107,390
St	itaff costs	476,763	387,652
Ad	Advertising	0	40,741
0	Other costs	86,535	122,200
		679,952	657,983

#### 9 Staff

There are 11 staff (2020:10) employed by University College London Hospitals NHS Trust contracted to work for the Charity. Staff costs are charged to the Charity on the basis of the time spent working for the Charity.

The total staff costs recharged were £509,224 (2020: £422,083). In addition, temporary staff were paid a total of £32,325 (2020: £20,588).

There was one (2020: one) member of key management personnel. The individual is directly employed by University College London Hospitals NHS Trust. The recharge paid by the charity to University College London Hospitals NHS Trust contributes towards the cost of this individual providing a managerial service. There are no employees employed directly by the Charity.

The Trustees receive no remuneration (2020: £nil) and no reimbursement of expenses (2020: £nil).

There were no other contracts or transactions with Trustees or connected parties.

The Charity is grateful for a number of charitable donations totalling £16,053 from 15 Trustees.

#### 10 Net incoming resources

This is stated after charging:	2021	2020
Operating lease rental - premises	81,808	81,808
Auditors' remuneration - Audit fees	14,541	11,940

11 Fixed asset investments		
	2021	2020
Market value of equities and bonds at 1st April	5,167,467	5,820,268
Additions at cost	500,000	-
Disposals at opening market value		
Net unrealised gains/(losses) on revaluation at 31st March	1,031,975	(652,801)
Market value of equities and bonds at 31st March	6,699,442	5,167,467
Cash deposits	867,275	630,857
Market value at 31st March	7,566,717	5,798,324
Historic cost at 31st March	6,140,514	5,759,932
Portfolio at 31st March	2021	2020
Multi-asset fund	6,699,442	5,167,467
Equities UK Unit Trusts	=	-
Sterling fixed interest	-	-
Cash - Sterling	867,275	630,857
Market value at 31st March	7,566,717	5,798,324
Holdings greater than 5% of the total market value of the portfolio at year end	2021	2020
Holding	Market value	
Multi-asset fund	6,699,442	5,167,467
Cash	867,275	630,857
12 Debtors	2021	2020
Interest receivable	50	176
Prepayments	61,065	32,425
Other receivable	68,166	311,630
	129,281	344,231

13	Creditors				202	1	2020
	Due within one year				202	-	2020
	University College London, Institute of New Other creditors and accruals	urology			430,68 124,73		474,485 56,767
_					555,42	0	531,252
14	Unrestricted funds: movements in year						
		Balance 1.4.20	Income	Expenditure	Investment gains/(losses)	Transfers	Balance 31.3.21
	Designated funds						
	National Hospital - small projects	70,488	-	(10,774)			59,714
	Neuroimaging Analysis Centre	93,813	_			(93,813)	-
	Neuro-oncology Flagship Programme	65,000	_			(35,000)	30,000
	Neurorehab - high dose Aphasia	98,482		249			98,731
	Physician Associate	100,000	-	(45,806)		(45,806)	8,388
	Stroke Project	700,000	_				700,000
	Theatres Appeal Fund	961,645	-	(430,689)		(276,956)	254,000
	Neuroscience Centre - Gray's Inn Road		-	-	-	1,500,000	1,500,000
	Total designated funds	2,089,428	-	(487,020)	-	1,048,425	2,650,833
	General fund	514,702	2,118,216	(1,040,405)	1,031,975	(1,225,454)	1,399,034
		2,604,130	2,118,216	(1,527,425)	1,031,975	(177,029)	4,049,867
15	Restricted Funds: movements in year						
		Balance 1.4.20	Income	Expenditure	Investment gains/(losses)	Transfers	Balance 31.3.21
	Neurodegeneration (NDG)						
	Neurodegeneration (NDG)	40,432	13,177	(20,585)			33,024
	Centre for Neuromuscular Diseases	510,840	58,208	(183,184)		(22,204)	363,660
	CJD	1,917	-	-		, ,	1,917
	Dementia Research	457,355	23,741	(11,000)			470,096
	Posterior Cortical Atrophy - new		292,988	-			292,988
	FTD - Picks Disease Support Group	28,633	2,106	-			30,739
	FTD - Picks Disease Research Fund	213,027	73,855	(141,205)			145,677
	Myrtle Ellis	=	90	-			90
	Rare Dementia Centre	88,799	142,359	(11,711)			219,447
	Rare Dementia Support Group	353,105	389,641	(233,179)			509,567
	Dystonia Research	3,000	-	-			3,000
	Myotonic Dystophy Research	3,000	490	=			3,490
	Parkinson's Disease		151				151
	Subtotal	1,700,108	996,806	(600,864)	-	(22,204)	2,073,846

#### 15 Restricted Funds: movements in year (continued)

	Balance 1.4.20	Income	Expenditure	Investment gains/(losses)	Transfers	Balance 31.3.21
Subtotal brought forward	1,700,108	996,806	(600,864)	=	(22,204)	2,073,846
Neurosurgery (NSG)						
Neurosurgery (NSG)	62,107	27,131	_			89,238
Acute Brain Injury	21,668	_	_			21,668
Brain Tumour Unit	150,120	10,172	-		35,000	195,292
Molly's Fund	74,883	20,322	_			95,205
Medical Intensive Therapy Unit	9,008	_	_			9,008
Neurocritical Care	1,965	_	_			1,965
Neurosurgical Education	2,396	_	_			2,396
Operating Theatres	9,571	_	_		(9,571)	_
Pituitary Surgery	29,427	=	=		( ' /	29,427
Spinal Injuries			=			-
Sub Arrachnoid Haemorrhage	12,672	325	(389)			12,608
Surgical Intensive Therapy Unit	167,595		-			167,595
Neurology (NRL)						
Neurology (NRL)	_	22,373	(19,109)			3,264
Epilepsy	-	,-	(,)			-
Epilepsy TMS - EEG	(6,813)	_	-		6,813	_
Mitochondrial Diseases (J Land)	50,000		_		0,010	50,000
MS Fund	148,363	_	_			148,363
MS Primary Progressive	20,000		_			20,000
Neuro-ophthalmology	9,980	_	=			9,980
Neuro-otology	21,915	_	(664)			21,251
Neuro-rehabilitation	49,734	6,584	(00+)			56,318
Neurorehab- High dose Aphasia	-5,75-	14,082	_			14,082
Neuro-urology		14,002	_			14,002
Research Fund	37,475	125	_			37,600
Stroke Project	232,758	1,584	_			234,342
Stroke Research	26,650	-	-			26,650
Education and Staff Development (ESD)						
Education and Staff Development (ESD)	(50,605)	775	_		45,806	(4,024)
Gorlov Prize	4,250	, , 3	(500)		13,000	3,750
Physician Associate	7,230		(500)			5,750
Queen Square History Book	(18,086)	1,750	_		16,336	_
Queen Square Textbook (Neurology)	(±0,000)	1,750	_		10,000	_
Somary	=		=			_
Staff Development			-			-
Subtotal	2,767,141	1,102,029	(621,526)	-	72,180	3,319,824

#### 15 Restricted Funds: movements in year (continued)

	Balance 1.4.20	Income	Expenditure	Investment gains/(losses)	Transfers	Balance 31.3.21
Subtotal brought forward	2,767,141	1,102,029	(621,526)	-	72,180	3,319,824
Queen Square (QSQ)						
Queen Square (QSQ)	15,235	31,075	-			46,310
Day Care Fund (£40k)	18,116	500	(40,820)		22,204	_
Small Acorns Programme (£40k/yr)	56,857	6,057	(35,271)			27,643
Wards/Nursing	16,549	-	-			16,549
Emergency Fund (income to QSQ)	-	21,273	(12,260)			9,013
Gray's Inn Road	-	1,889	_			1,889
	=			=		
Technology and Innovation (T&I)			-			-
Technology and Innovation (T&I)	-	11,820	(18,960)			(7.140)
Innovation Fund	90,230	81,603	(16,741)			155,092
Neuroimmunology	133,488	13,266	-			146,754
Neuroimmunotherapy Clinical Trial - £250k 2018/19	111,619	39,511	(128,333)			22,797
Paul Mulholland Clinical trials			-			_
Neuropsychology Project (£155k)	(22,672)	8,305	(38,122)		52,489	_
Neuroresponse (£250k)	-	-	(30,156)		30,156	-
TOTAL RESTRICTED FUNDS	3,186,563	1,317,328	(942,189)	_	177,029	3,738,731

#### 16 Restricted Funds: movements 2019-20

	Balance 1.4.19	Income	Expenditure	Investment gains/(losses)	Transfers	Balance 31.3.20
Neurodegeneration (NDG)	10,935	34,813	_		(5,316)	40,432
Centre for Neuromuscular Diseases	614,066	25,311	(128,537)		(3,310)	510,840
CJD	1,917	20,011	(120,007)			1,917
Dementia Research	473,374	15,226	(31,245)			457,355
FTD - Picks Disease Support Group	28,064	569	-			28,633
FTD - Picks Disease Research Fund	138,413	79,055	(4,441)			213,027
Myrtle Ellis	-	120	(120)			-
Rare Dementia Centre	75,000	13,799	. ,			88,799
Rare Dementia Support Group	214,702	330,557	(192,154)			353,105
Dystonia Research	3,000	-	-			3,000
Myotonic Dystonia Research		3,000	-			3,000
Parkinson's Disease	9,584	100	(15,000)		5,316	-
Neurosurgery (NSG)	33,839	28,268	-			62,107
Acute Brain Injury	21,758	-	(90)			21,668
Brain Suite	9,436	-	-		(9,436)	-
Brain Tumour Unit	149,365	755	-			150,120
Molly's Fund	56,236	20,234	(1,587)			74,883
Medical Intensive Therapy Unit	9,008	-	-			9,008
Neurocritical Care	1,965	-	-			1,965
Neurosurgical Education	2,396	-	-			2,396
Operating Theatres	110	25	-		9,436	9,571
Pituitary Surgery	29,427	-	-			29,427
Sub Arrachnoid Haemorrhage	13,118	-	(446)			12,672
Surgical Intensive Therapy Unit	167,343	252	-			167,595
Neurology (NRL)	7,277	2,950	-		(10,197)	30
Epilepsy	13,518	-	-		(13,518)	-
Epilepsy TMS - EEG	-	-	(30,588)		23,745	(6,843)
Mitochondrial Diseases (J Land)	50,000	-	-			50,000
MS Fund	148,300	63	-			148,363
MS Primary Progressive	20,000	-	-			20,000
Neuro-ophthalmology	9,980	-	-			9,980
Neuro-otology	22,663	-	(748)			21,915
Neuro-rehabilitation	24,742	24,992	-		101510	49,734
Neurorehab - high dose Aphasia	96,086	61,121	(258,725)		101,518	=
Pain Management	30	-	-		(30)	-
Research Fund	37,475	-	-			37,475
Stroke Project	147,866	84,892	-			232,758
Stroke Research	26,650	-	-			26,650
Subtotal	2,667,643	726,102	(663,681)	_	101,518	2,831,582
			, ,			

#### 16 Restricted Funds: movements 2019-20 (continued)

	Balance 1.4.19	Income	Expenditure	Investment gains/(losses)	Transfers	Balance 31.3.20
Subtotal brought forward	2,667,643	726,102	(663,681)	=	101,518	2,831,582
Education and Staff Development (ESD)						
Gorlov Prize	18,633	658	(95,806)		25,910	(50,605)
Queen Square History Book	4,750	-	(500)			4,250
Queen Square Textbook (Neurology)	(19,034)	948	_			(18,086)
Somary	18,599	6,051	_		(24,650)	·
Staff Development	1,260	-	-		(1,260)	-
Queen Square (QSQ)	6,110	9,125	-			15,235
Day Care Fund	18,750	2,580	(3,214)			18,116
Small Acorns Programme	60,617	18,981	(22,741)			56,857
Wards/Nursing	16,549	-	-			16,549
Technology and Innovation (T&I)	32,531	23,502	-		(56,033)	-
Innovation Fund	98,885	43,845	(52,500)		,	90,230
Neuroimmunology	23,689	109,799	·			133,488
Neuroimmunology Clinical Trial	(29,522)	141,771	(630)			111,619
Neuropsychology Project	=	3,270	(82,387)		56,445	(22,672)
Neuroresponse	30,000	-	(29,588)		(412)	_
Total Restricted funds	2,949,460	1,086,632	(951,047)	-	101,518	3,186,563

#### 17 Analysis of net assets between funds

	Fixed investments	Net current assets	Total 2021	Total 2020
General fund Designated funds	750,000	649,034	1,399,034	514,701
	4,816,717	(2,165,884)	2,650,833	2,089,428
Total unrestricted funds Restricted funds	5,566,717	(1,516,850)	4,049,867	2,604,129
	2,000,000	1,738,731	3,738,731	3,186,563
	7,566,717	221,881	7,788,598	5,790,692

#### 18 Operating lease commitments

 $At 31 \, \text{March 2021 the charity had total commitments under non-cancellable operating leases of land \& buildings as set out below: \\$ 

Payable as follows:	2021	2020
Up to one year Two - five years	- ,	81,108 101.385
More than five years	20,277	101,363

#### 19 Related party transactions

There were no related party transactions during the year (2020: nil) that require disclosure in the financial statements.



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