



20
21



600,000

adults, children and babies are living with epilepsy in the UK

180,000

have NO treatment options and live with uncontrolled seizures

600

more will be told they have epilepsy this week, another 600 next week and 600 more the week after that...

GOING FURTHER THAN EVER BEFORE

We know behind these numbers are much loved family members and friends. **We share** their frustration that epilepsy continues to interrupt lives. **We see** the relentless devastation it continues to cause. **We know** research investment is currently too low.

We will go further than ever to transform epilepsy research.

In 2019, we adopted a new approach to help change the landscape of epilepsy research with our Going Further strategy. During 2019/20 we were making real and immediate progress with it. We had launched a campaign to highlight the lack of funding in epilepsy research. We had developed our SHAPE NETWORK to involve people with epilepsy in all aspects of research, from identifying and evidencing research priorities to making decisions on the projects we fund. We had created new awards to attract the brightest and best research minds and get them focused on unlocking the secrets of epilepsy.

Then, COVID-19 hit. Everything we do to beat epilepsy had to adapt – from how we fundraise and carry out research, to the way our staff work. As we wrestled with the big epilepsy research challenges in front of us, we were also trying to limit the damaging impact of COVID-19 on our research.

The strength of our community

This past year our Epilepsy Research UK community united like never before. Our supporters took to fundraising in their living rooms. Our researchers left the labs and took to their desks to analyse data and share their findings. Our staff left the office and worked at kitchen tables to push forward our vision of a life free of epilepsy.

No action is too small to make a difference. Every day in the lab, every pound donated and every piece of research published all add up to extraordinary breakthroughs.

In 2020/21, our supporters donated over £1 million. In this review, you'll see the action we took during the pandemic and the progress we were still able to make towards achieving our vision of a life free from epilepsy.

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MESSAGE FROM OUR CHAIR & CEO



This year has been testing for Epilepsy Research UK. As we excitedly embarked on implementing our ambitious strategy Going Further, we never thought the world would come to a standstill.

The impact of the pandemic on people living with epilepsy has been severe, with many experiencing more seizures due to the increased stress, loss of sleep and high fevers. Access to medicines remain a concern and waiting times for epilepsy surgery and video telemetry have increased substantially - putting people with uncontrolled epilepsy at increased risk of sudden unexpected death.

We're not out of the woods yet. This is an ongoing crisis, and the severity of the situation has hugely impacted our ability to raise funds for research and the ability of our researchers to continue their studies.

Despite the many challenges we've faced, we are proud that ERUK has continued to be the driving force behind epilepsy research. Over the past year our community used its skills and expertise to respond with creativity and innovation to continue our mission.

In the midst of all the various lockdowns, we've seen ERUK at its most agile and responsive. Though delayed by the pandemic, we continue to forge ahead with our strategy. This year, thanks to two exceptionally generous legacies, we've been able to award £1.3m to 18 exciting new projects.

We've launched virtual fundraising events so our amazing supporters could stay connected.

We developed an online programme of events to continue the information sharing and collaborations vital for future breakthroughs. And, we rapidly put plans in place to protect our researchers from the damaging impact of COVID-19, by increasing funding and extending deadlines.

It's been heartening to see in these uncertain times how our supporters have stood by us, and by doing so have enabled us to stand by our funded researchers. Our researchers too have shown great resilience. When they were forced to close the door to their laboratories, they opened their laptops - analysing and publishing research data, moving studies online, making new applications for funding and writing research papers.

COVID-19 has made us rethink how we can maximise the impact of research. We don't just want to get back to the pre-pandemic days, we want epilepsy research to be even stronger than before.

With the strength of our researchers, supporters and staff we will continue to navigate our way through these uncertain times. Thank you for being a much valued member of our community – and together we will not only recover, but will strengthen research into epilepsy for the future.

Thank you.

Professor Matthew Walker, Chair of Trustees
Maxine Smeaton, Chief Executive

EPILEPSY RESEARCH UK IS FUNDING...

18 NEW STUDIES THIS YEAR

60 RESEARCHERS

58 RESEARCH PROJECTS IN TOTAL



Research grants in 2020/21

This year we awarded seven research grants totalling £1,242,406 each one looking at a particular aspect of the cause, prevention or treatment of epilepsy. Our two Doctoral Training Centre Grants awarded this year will support a total of 13 individual research projects. We also awarded £78,560 in costed extensions to existing grants in response to delays and setbacks as a result of COVID-19. This brings the total investment in research in 2021 to £1,320,966.

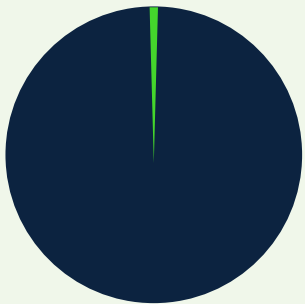
PRINCIPAL INVESTIGATOR, INSTITUTION	TITLE	AMOUNT
Professor Markus Reuber University of Sheffield	Comparing interactions in remote and face-to-face seizure clinic consultations	£49,979
Professor Sameer Zuberi University of Glasgow	Evaluation of a new clinical service to allow video sharing and remote care for people with epilepsy	£49,726
Dr Rhys Thomas Newcastle University	Epilepsy risk reduction and e-education: Reducing holistic epilepsy-risks during the COVID-19 pandemic	£49,618
Dr Tim Tierney University College London	Bedside Brain Imaging	£293,942
Dr Gareth Morris University College London	Using microRNA biosignatures as sensors for precision gene therapy	£299,141
Professor Richard Chin Professor Cathy Abbott University of Edinburgh	Doctoral Training Centre: Six PhD research studies focussed on improving outcomes for Childhood Onset Epilepsies: from mechanisms to treatment	£250,000
Dr Rhys Thomas Professor Andrew Trevelyan Newcastle University	Doctoral Training Centre: Six PhD research studies investigating epilepsy, from laboratory to clinic. Computational and technological solutions to challenging pathology	£250,000
Costed extensions in response to delays due to COVID-19 were awarded to:	Professor Kirill Volynski, University College London Professor Mark Richardson, Kings College London Dr Jessica Kwok, University of Leeds Dr Gabriele Lignani, University College London Dr Vincent Magloire, University College London	£78,560
Total grants awarded		£1,320,966

In addition, we are currently funding 43 other projects, approved in prior years, at institutes around the country, examples of which include investigating the potential use of breath testing and artificial intelligence for diagnosing epilepsy, using global data to identify risk markers for sudden unexpected death in epilepsy (SUDEP), investigating the best surgical techniques for tumour associated epilepsy and the pioneering use of gene therapy for treating epilepsy.

SHINING A LIGHT ON THE FUNDING PROBLEM

A staggering 100,000 emergency admissions are due to epilepsy each year costing the NHS an estimated £1.5 billion annually. Despite this, there is an alarming lack of funding for epilepsy research. Action is urgently needed to address this, which is why last year we launched our #ALifeInterrupted campaign to raise awareness of the disparity in research funding.

Research into epilepsy receives only 0.3% of the £4.8 billion total spent on health-related research in the UK.



- epilepsy research
- other health-related research

SHAPE NETWORK

As part of our campaign, we launched our SHAPE NETWORK. This network will provide an opportunity for people with epilepsy, their carers and families to get involved in all aspects of epilepsy research, from identifying and evidencing research priorities to making decisions on the research projects we fund.

Through this network we will be able to ensure research is focused on the most important outcomes for people living with the condition, and will provide the evidence needed to secure greater research funding.

Capacity building epilepsy research by providing a national PPI service

Our network will provide a new national Patient and Public Involvement (PPI) service to all clinical and scientific researchers undertaking research into epilepsy in academic and clinical institutions throughout the UK. This national PPI service to researchers will facilitate and manage the involvement of people living with epilepsy in research.

90%
of people with
epilepsy said their
condition affects
their day to day lives

Over 1,000
emergency hospital
admissions related to
epilepsy happen every
week in England



#ALifeInterrupted

OUR RESPONSE TO COVID-19



Professor Hannah Cock
Epilepsy Research UK Scientific Advisory Committee member
St George's Hospital, Tooting

OUR RESPONSE TO COVID-19

The beginning of 2020 signalled the start of an exciting time for ERUK. We were implementing year one of our new strategy Going Further, and funding more research than ever before. Then in March, everything changed. The COVID-19 outbreak meant we had to quickly realign our priorities.

As an organisation, we decided to focus on four key areas to limit the impact of the pandemic and help to ensure research into epilepsy was protected.



1. SUPPORT INNOVATIONS IN HEALTHCARE

COVID-19 disrupted how people with epilepsy were able to manage their condition and how health services provided assessment, diagnosis and treatments. New technologies and remote consultations for routine and emergency care were adopted at a pace never seen before. To drive the development of new innovations for people with epilepsy during this time, we put out an urgent call for research proposals in July. Following this urgent call we funded three projects.

Prof Markus Reuber
£49,979



COMPARING INTERACTIONS IN REMOTE AND FACE-TO-FACE SEIZURE CLINIC CONSULTATIONS

Due to the pandemic people with epilepsy were speaking to their neurologists over the phone or the internet rather than face-to-face. While these teleconsultations are more convenient for people with epilepsy they also present challenges. This research project will improve teleconsultations, not only for the duration of the pandemic, but in the long-term for both people with epilepsy and clinicians.

Prof Sameer Zuberi
£49,726



EVALUATION OF A NEW CLINICAL SERVICE TO ALLOW VIDEO-SHARING AND REMOTE CARE FOR PEOPLE WITH EPILEPSY

This research project aims to find ways to utilise mobile devices so that patients and carers can share films to help speed up diagnosis and reduce unnecessary hospital visits. The study was developed following feedback from patients who wanted a secure way to share their films with healthcare professionals.

Researchers developed a secure video-sharing platform which enables people with epilepsy and their families to share videos of seizures with their doctor using their smartphone. Where this platform has been used, clinicians found unexpected benefits beyond more rapid diagnosis, saving on tests and reduced clinic appointments. Families say they feel more connected to the team and healthcare professionals report feeling more empathy for patients as they see the impact of seizures in the home environment.

Dr Rhys Thomas
£49,618



EPILEPSY RISK REDUCTION AND E-EDUCATION: REDUCING HOLISTIC EPILEPSY RISKS DURING THE PANDEMIC

This study seeks to reduce any risks associated with the move towards remote working by introducing Gold Standard safety tools. Researchers will create a series of videos aimed at specific vulnerable groups to ensure that people with epilepsy have the opportunity to hear about epilepsy safety. The study will also design new ways of communicating the risk to both patients and healthcare professionals.

2. PROTECT OUR RESEARCHERS

As soon as lockdown was announced we offered our immediate support to ERUK researchers, extending deadlines and increasing funding. We awarded costed extensions to researchers such as Dr Jessica Kwok and Professor Kirill Volynski to save their research from being lost to the pandemic.



Dr Jessica Kwok

CONTINUING IMPORTANT WORK ON ABSENCE SEIZURES

Absence seizures are a common form of childhood epilepsy that are often very difficult to treat. Very little is known about what causes absence seizures and this is what Dr Jessica Kwok’s research sets out to investigate.

Dr Kwok’s team are looking at the role of an extracellular structure called a perineuronal net (PNN) in causing epilepsy. The results of this research will be used to guide the design of new drugs to treat absence seizures.

RESEARCHING THE LINKS BETWEEN SEIZURES AND MIGRAINES

Epilepsy and migraines exhibit substantial similarities. Both are episodic, several antiepileptic drugs are effective in treating migraines and both seizures and migraines share mechanisms in common. Mutations of the same genes can lead either to epilepsy or to a severe form of migraine with aura (flashing lights or tingling sensations) and an aura-like mechanism has been linked with sudden unexpected death in epilepsy (SUDEP). However, the mechanisms that steer the brain to either a seizure or an attack of migraine remain poorly understood. Professor Kirill Volynski’s research aims to better understand this link to inform new pharmaceutical targets in the future.



Prof Kirill Volynski

3. SECURE OUR INCOME

COVID-19 has had a huge impact on our ability to raise funds. Like many charities, we have experienced a 50% drop in voluntary income due to the cancellation of mass participation events and community fundraising activities.

Despite the magnitude of the challenges faced, our staff showed resilience and tenacity. Their quick responses led to the development of a range of virtual fundraising products to generate income. These swift actions, coupled with the generosity of our supporters and the capacity of our reserves, put us in a strong position to come through the crisis.



4. SHARE INFORMATION

An important part of our work is keeping people living with epilepsy and our supporters informed about the research we fund. We also seek to encourage the sharing of knowledge and information between clinicians and researchers to help accelerate progress. During lockdown we implemented a digital programme of information sharing to support scientific networking, information exchange and faster access to new research findings.

RESEARCH ROUNDTABLE

Our roundtable webinars provided the opportunity for clinicians, researchers and people affected by epilepsy to discuss the often complex topics of research and epilepsy. The hour-long sessions included topics such as SUDEP, research participation and our Innovations in Healthcare Awards Night.



RESEARCH BLOG

In April 2020 we launched our Research Blog to provide an opportunity for clinicians, scientists and people with epilepsy to discuss and demystify research. Every month we focused on a different theme such as epilepsy in childhood and promising new treatments.



MOST POPULAR BLOG OF 2020

In the most popular blog from 2020, ERUK Emerging Leader Fellow, Dr Gabriele Lignani, talked us through his pioneering research into gene therapy and what the latest discoveries in this area could mean for people with epilepsy.

OVER 10,000
WEBINAR VIEWS*

OVER 13,000
BLOG VIEWS

*since launching our series at the end of May 2020

RECOVERY AND RENEWAL



Dr Vincent Magloire
Epilepsy Research UK Emerging Leader Fellow 2019

RECOVERY AND RENEWAL CAPACITY BUILDING EPILEPSY RESEARCH FOR THE FUTURE

Our work this past year has not just been focused on protecting epilepsy research from the impact of the pandemic, it was also focused on capacity building the epilepsy research environment to ensure we don't just maintain our momentum, but accelerate it.



We want the post-pandemic world to look different to the one we had before. We want to mobilise research funders, government and pharmaceutical companies to invest in transforming research into epilepsy.

We also want to drive up the numbers of scientists seeking to focus their career in the field of epilepsy research. To do this we've continued to concentrate our efforts on attracting the best and brightest minds to epilepsy research and supporting their development at all career stages, from PhD students to Professors.

We took the difficult decision not to fund the Explore Pilot and Endeavour Project studies in the 2020/21 grant round and instead focused our investment on our ERUK Emerging Leader Fellowship Awards and our Doctoral Training Centre Grant scheme to build future generations into international leaders.

Every £1 invested by Epilepsy Research UK has generated a further **£5.82** for research into epilepsy.



FELLOWSHIP AWARD

Our fellowships awards allow us to attract the best early career researchers, develop their scientific expertise and place them at the heart of epilepsy research. This commitment to supporting the careers of researchers through these awards is helping to strengthen epilepsy research capacity in the UK.

Dr Gareth Morris
£299,141



EPILEPSY RESEARCH UK EMERGING LEADER FELLOWSHIP AWARD

Department of Neuroscience,
Physiology and Pharmacology
University College London
Dr Gareth Morris

This award will fund Dr Gareth Morris' research in a new method of precision gene therapy using microRNA biosignatures as sensors. 'Gene therapy' is a promising new way to control seizures but it has some limitations. Not all brain cells are involved in seizures, and we don't have a way to direct therapies towards the seizure-generating cells only, leaving the non-seizure cells alone. We know that there are molecules called 'microRNAs' which are present in unusually high amounts in seizure-generating brain cells. Dr Morris proposes that we can take advantage of these natural microRNAs to activate gene therapies only in specially targeted seizure-generating brain cells.

ERUK-FUNDED RESEARCH MAKING AN IMPACT

Despite extensive research, around 75% of people with temporal lobe epilepsy still experience seizures that can't be well controlled with medication. Even when medication does control seizures, people can experience unwanted side effects. The new technique proposed by Dr Morris could hugely refine how we treat temporal lobe epilepsy and other drug-resistant epilepsies. It could represent a 'one-off' treatment, and may mean that people with epilepsy no longer require medications to control their seizures.

ERUK-FUNDED RESEARCH MAKING AN IMPACT

This project will develop a sensor, known as the radio frequency magnetometer, that can be worn in a normal hospital ward or residential setting while being sensitive to the brain activity produced in epilepsy. This study offers the potential to eliminate the need for invasive assessments and provide enhanced surgical planning at a much younger age for many more children, at much reduced cost and risk.

Dr Tim Tierney
£293,942



EPILEPSY RESEARCH UK & YOUNG EPILEPSY FELLOWSHIP AWARD

Wellcome Centre for Human
Neuroimaging
University College London
Dr Tim Tierney

For many young people living with epilepsy neurosurgery is the only treatment option. Surgical planning relies heavily on brain imaging and the younger the person, the more likely the surgery will be successful. However, younger children often struggle to remain still in conventional brain scanners. This movement severely degrades image quality and can result in delays in neurosurgery. Dr Tierney's team have developed a wearable brain scanner that can deliver enhanced quality images, even when a child is moving. Unfortunately, these scanners can only function in specialised and expensive magnetically-shielded rooms, which few hospitals have.

DOCTORAL TRAINING CENTRE GRANT SCHEME

Launched last year this scheme is to support PhD students to create future leaders in epilepsy research. The scheme places a strong emphasis on career development and mentorship.

EPILEPSY RESEARCH UK & NEWCASTLE UNIVERSITY
DOCTORAL TRAINING CENTRE

£250,000 with matched funding from Newcastle University
Professor Andrew Trevelyan, Dr Rhys Thomas

In 2020/21 we awarded Newcastle University £250,000 (match-funded by Newcastle University) for six PhD students. Rapid advances in technology allows the analysis of the complex origins of seizures and offers novel solutions to monitor and treat the condition. The team at Newcastle University are experts in molecular biology, computer programming and engineering. They will be working on six innovative projects covering three areas of epilepsy research:

- how seizures happen
- how to predict when seizures may occur
- how to prevent seizures.



Professor Andrew Trevelyan



Dr Rhys Thomas



Professor Richard Chin



Professor Cathy Abbott

EPILEPSY RESEARCH UK & EDINBURGH UNIVERSITY
DOCTORAL TRAINING CENTRE

£250,000 with matched funding from Edinburgh University
Professor Richard Chin, Professor Cathy Abbott

In 2020/21 we awarded Edinburgh University £250,000 (match-funded by Edinburgh University) for six PhD students.

The cause of epilepsy is unknown in most children, however recent advances in gene sequencing have revealed a considerable number of cases result from an abnormality in a single gene. This gene provides a target for researchers and allows them to study causes and treatment of childhood-onset epilepsies in a simplified experimental system.

This study will bring together experts in basic science and clinical skills to lead PhD research projects to improve understanding of how seizures occur and improve methods of diagnosis, whilst preparing the researchers for a career in epilepsy research.

FINAL REPORT FROM OUR 2018 EMERGING
LEADER FELLOWSHIP AWARD

Trainee neurosurgeon Mr Ashan Jayasekera was awarded the 2018 Emerging Leader Fellowship Award to investigate epilepsy that occurs as a result of a brain tumour. Mr Jayasekera set out to demonstrate that areas of brain around a tumour with high levels of glutamate could be responsible for generating seizures.



ERUK-FUNDED RESEARCH
MAKING AN IMPACT

As part of the research, patients had MR spectroscopy scans prior to their surgery, and a sample of tissue was analysed for any spontaneous seizure activity. Mr Jayasekera discovered that tissue with spontaneous seizures in the lab came from areas of the brain around a tumour with high glutamate levels. This is the first time this has been demonstrated and is the first step in showing that MR spectroscopy can be used in mapping the areas of brain responsible for seizures in patients with gliomas.

“The Emerging Leader Fellowship Award enabled me to pause my clinical training and focus on an area of research I strongly feel is an unmet need; treating seizures in patients with brain tumours. I’m grateful to the hardworking and generous ERUK supporters for funding this important area of research, and me as an aspiring clinical academic. Working with patients who give up their time so generously to be part of research is an ongoing privilege and the driving force for me to carry on this work.”
Mr Ashan Jayasekera



THE COIN STUDY

Dr Charlotte Tye, King’s College London, is researching the impact of the COVID-19 pandemic on the mental health and wellbeing in families of children with rare genetic and neurodevelopmental disorders, many of whom also have epilepsy. Even under normal circumstances, we know that behavioural difficulties greatly impact upon quality of life in individuals with rare syndromes and that families can experience anxiety, stress and low mood. The sudden change to daily life, such as carefully established routines and relationships, support networks and professional support, combined with a higher risk of infection is likely to impact upon wellbeing in both children and their parents, and even worsen existing difficulties. The findings of the CoIN study will be used to inform how we can best support families both now and in future disruptive emergencies.

GOING FURTHER



Amanda, John and children
Epilepsy Research UK supporters

GOING FURTHER

Our strategy is broken down into three priority areas of research. Every project or person we fund, and every action we take fits into one of these priorities. This targeted approach is to ensure we can maximise our resources and deliver real benefits to people living with epilepsy as quickly as possible.



OUR VISION:

A LIFE FREE FROM EPILEPSY

OUR PURPOSE:

DRIVING AND ENABLING LIFE CHANGING
LIFE SAVING RESEARCH INTO EPILEPSY

OUR PRIORITIES:

Promote, encourage and fund research into the causes, and diagnosis of epilepsy and clinical management of people with epilepsy and associated conditions.

Develop the next generation of epilepsy researchers and capacity build the epilepsy research environment.

Accelerate innovations for people with epilepsy by supporting and commissioning research that will influence clinical practice and health policy.

VALUES:

IMPACTFUL RIGOROUS INNOVATIVE COLLABORATIVE

THREE PRIORITY AREAS OF RESEARCH



Promote, encourage and fund research into the causes, diagnosis and treatment of epilepsy, and clinical management of people with epilepsy and associated conditions.



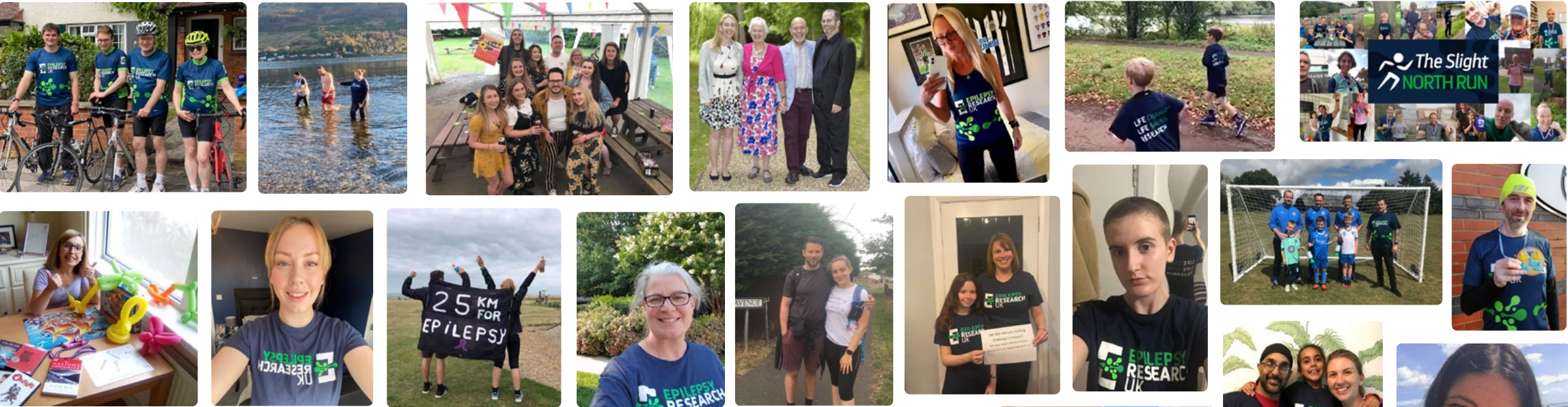
Develop the next generation of epilepsy researchers and **capacity-build the epilepsy research environment.**



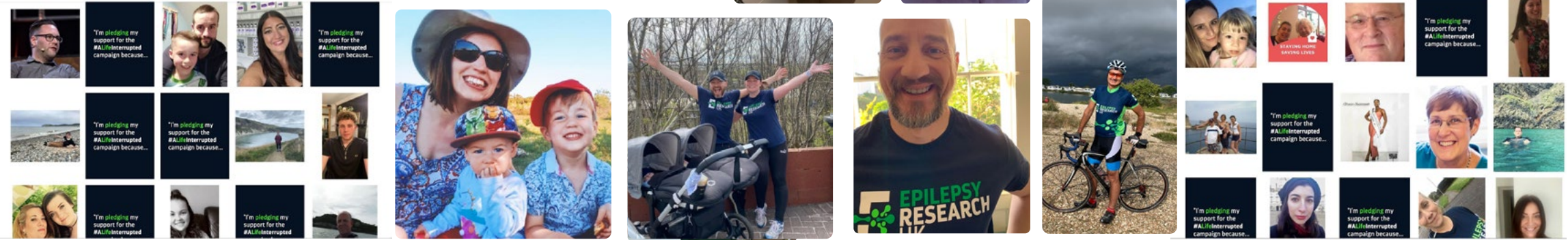
Accelerate innovations for people with epilepsy by supporting and commissioning research that will influence clinical practice and health policy.

LOOKING FORWARD - THIS YEAR WE WILL:

- Continue to build the largest ever community of people living with epilepsy to influence and shape research. Our SHAPE NETWORK will involve people with epilepsy in all aspects of epilepsy research, from identifying and evidencing research priorities to making decisions on the projects we fund.
- Embark on a Priority Setting Partnership with the James Lind Alliance to identify and prioritise the top ten unanswered research questions. We will share the top ten list of jointly agreed research priorities, to inform researchers, research funders and fellow epilepsy charities about priorities, so that they too can fund research most important to people living with epilepsy.
- There is a huge gap in knowledge on the prevalence and incidence of epilepsy, with existing data over ten years old. We are going to conduct a prevalence and incidence study to provide much-needed evidence of the overall burden of the condition.
- We will set up an epilepsy research membership body for rare epilepsies and associated conditions to give a greater voice to types of epilepsies that often get overlooked.
- With the information gathered from the above programmes of work, we will develop a research strategy that will clearly identify the types of research and scientific areas we will promote and support.



BECAUSE OF YOU



Everything we've been able to do this year is because of our amazing supporters. We've been blown away by your generosity, inspired by your tenacity and moved by the support you've shown to people living with epilepsy. In a year that has challenged us, you stood by Epilepsy Research UK.

HOW WE INVESTED THE MONEY YOU RAISED

£7.72 raised for every pound spent directly on fundraising in 2020/21

£400,000 was raised by people remembering ERUK in their Wills

A LASTING LEGACY FROM TWO SPECIAL PEOPLE

Two generous legacies enabled us to fund our research commitments in the 2020 and 2021 annual grant round, showing the lasting impact leaving a legacy can have.

LET'S STOP EPILEPSY INTERRUPTING LIVES

By continuing to support ERUK in the year ahead, you can help us to go further - fund more projects, attract more scientists and accelerate the pace of discovery for all people living with epilepsy, both today and tomorrow.

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

YEAR ENDING 31ST MARCH 2021

The directors hereafter referred to as the trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31st March 2021 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and 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).

Reference and administrative details

Directors and Trustees

The Directors of the charitable company and its trustees for the purposes of charity law serving during the year, and since the year end, were:

Professor Matthew Walker MA MB BChir FRCP PhD (Chair)
Mr Barrie Akin LLB FCA
Mr Joseph Brice BA (Hons) (appointed September 2020)
The Rt Hon David Cameron
Dr Anne Coxon DPsych
Professor Michael Cousin BSc PhD (appointed June 2020)
Ms Mary Gavigan BBS MA FCA
Dr John Hirst CBE BA FCA MCT CCBIM DSc
Mr Simon Lanyon
Mr Thomas McLaughlan BA (Hons) (appointed September 2020)
Professor Mark Richardson MA BMBCh MRCP PhD CCST FRCP
Mr Harry Salmon BA
Professor Stephanie Schorge BSc, PhD, SFHEA
Ms Judith Spencer-Gregson FCA MSc
Dr Rhys Thomas BSc, MBChB, MRCP, MSc, PhD
Ms Susan Usiskin (resigned December 2020)

President

Professor Helen Cross MB ChB PhD FRCP(UK) FRCPCH

Chief Executive

Ms Maxine Smeaton MSc PGDip MInstF

Independent auditors

F A Magee & Company, Chartered Accountants and Statutory Auditors, Wimborne House, 4-6 Pump Lane, Hayes, UB3 3NB

Bankers

CAF Bank Ltd, PO Box 289, Kings Hill, West Malling, Kent, ME19 4TA
Lloyds Bank, 308-312 Chiswick High Road, London, W4 1NS

Solicitors and Company Secretary

A J Lutley, Springfield, Rookery Hill, Ashted Park, Ashted, Surrey, KT21 1HY

Registered and Head Office

Charity number 1100394

Company number 4873718

CAN Mezzanine, 7-14 Great Dover Street
London SE1 4YR

Objectives and activities for the public benefit

The trustees have complied with their duty according to Section 17(5) of the Charities Act 2011. To achieve this, the Charity reports that it offers the following public benefit:

The objects of the charity are:

- to promote, encourage and finance research into epilepsy and associated conditions and their underlying causes;
- to promote and improve the treatment, care and welfare of persons affected by epilepsy and associated conditions; and
- to advance the general education and understanding of the public concerning the nature and causes of epilepsy and associated conditions and the treatment thereof.

In shaping our objectives for the year and planning our activities, the trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'. The objectives set out in the charity's business plan for the year are shaped by these aims with a view to funding an increasing programme of research, encouraging collaboration amongst researchers and raising awareness of the need for more funding for epilepsy research.

Key impacts of the global pandemic 2020/21

Income

Like the majority of charities in our sector, we have experienced a 50% drop in voluntary income due to the cancellation of mass participation events and community fundraising activities. In response we developed a range of virtual products, such as 6 for the 600, Ride for Research, Quiz Nights and a Lottery. We focused on stewarding and engaging our regular supporters and undertook targeted activities such as a mass mail out to over 400 Trusts and Foundations and campaigns to segmented groups of donors. We also invested in developing the Corporate proposition. Whilst these activities did not result in significant new funds, we did overachieve against the revised Covid Budget.

Research

We made a number of adjustments to our research activities during 2021/22.

- The International Expert Workshop 'Emerging Approaches in the Treatment of Epilepsy' scheduled for March 2021 was postponed.
- We supported costed and no-cost extensions to researchers who were unable to continue their work in the laboratory or on clinical trials due to lockdown
- We extended the deadline for our doctoral training centre programme which is designed to support institutions to create 'PhD hubs' to attract young researchers to the field of epilepsy and facilitate further

research and investment. Match funding was required by the host university.

- We took the decision not to fund the Explore Pilot and Endeavour Project studies and to only fund ERUK Emerging Leader Fellowship Awards in the grant round in 2020/21. We prioritised investment in to building capacity by supporting early-career scientists to develop into epilepsy research leaders with a view to reducing the risk of losing promising epilepsy focused research and researchers.

#ALifeInterrupted Campaign

The #ALifeInterrupted was initially planned as an integrated brand awareness/fundraising campaign, but given the abrupt reduction in voluntary giving, we shifted our approach to using summary data from the 2019 UK Health Research Analysis to produce a report highlighting the alarming inequalities in research funding and recommending that people with epilepsy take an active part in safeguarding the future of research. Our aim was to acquire a new audience and keep our current supporter base engaged and motivated about our work. The launch of #ALifeInterrupted at The Frances Crick Institute in May 2020 was postponed.

Volunteers

We are grateful for the significant support we receive from the members of the Trustee Board and the Scientific Advisory Committee who all provide their extensive knowledge, skills and experience in order to further the objects of the charity.

Going Concern

The Trustees are confident that whilst the pandemic has seriously impacted our income, this has not affected our going concern as we were holding unrestricted funds at 31 March 2021 of £1,943,543. The reserves policy has therefore proved to be adequate to enable Epilepsy Research UK to meet its commitments during the pandemic without any adverse impact on our research activities.

Plans for future periods

Epilepsy Research UK is uniquely positioned amongst the epilepsy charities to develop a plan to drive further investment into research innovations in diagnosis, treatments and prevention of epilepsy. We are also well placed to lead on the commissioning of research that will provide capacity-building evidence to support the work of all the epilepsy charities as well as clinical and lab-based researchers and health commissioners.

To develop an understanding of the impact of epilepsy and agree priorities we will, where possible, do this in collaboration with other key epilepsy charities, researchers and people with lived experience. The following key activities are proposed to help support the gathering of data from which to launch a significant campaign for strategic investment:

- Shape Network Roll Out
- Undertake a Priority Setting Partnership (PSPs) with the James Lind Alliance (JLA) -
- Commission a Prevalence & Incidence Study
- Develop Research Strategy Priorities

Research grants in 2021

This year we awarded seven research grants totalling £1,242,406, each one looking at a particular aspect of the cause, prevention or treatment of epilepsy. Our two Doctoral Training Centre Grants awarded this year will support a total of 13 individual research projects. We also awarded £78,560 in costed extensions to existing grants in response to delays and setbacks as a result of COVID-19. This brings the total investment in research in 2021 to £1,320,966.

Summary of research grants awarded

PRINCIPAL INVESTIGATOR, INSTITUTION	TITLE	AMOUNT
Professor Markus Reuber University of Sheffield	Comparing interactions in remote and face-to-face seizure clinic consultations	£49,979
Professor Sameer Zuberi University of Glasgow	Evaluation of a new clinical service to allow video sharing and remote care for people with epilepsy	£49,726
Dr Rhys Thomas Newcastle University	Epilepsy risk reduction and e-education: Reducing holistic epilepsy-risks during the COVID-19 pandemic	£49,618
Dr Tim Tierney University College London	Bedside Brain Imaging	£293,942
Dr Gareth Morris University College London	Using microRNA biosignatures as sensors for precision gene therapy	£299,141
Professor Richard Chin Professor Cathy Abbott University of Edinburgh	Doctoral Training Centre: Six PhD research studies focussed on improving outcomes for Childhood Onset Epilepsies: from mechanisms to treatment	£250,000
Dr Rhys Thomas Professor Andrew Trevelyan Newcastle University	Doctoral Training Centre: Six PhD research studies investigating epilepsy, from laboratory to clinic. Computational and technological solutions to challenging pathology	£250,000
Costed extensions in response to delays due to COVID-19 were awarded to:	Professor Kirill Volynski, UCL Professor Mark Richardson, KCL Dr Jessica Kwok, University of Leeds Dr Gabriele Lignani, UCL Dr Vincent Magloire, UCL	£78,560
Total grants awarded		£1,320,966

In addition, we are currently funding 43 other projects, approved in prior years, at institutes around the country, examples of which include investigating the potential use of breath testing and artificial intelligence for diagnosing epilepsy, using global data to identify risk markers for sudden unexpected death in epilepsy (SUDEP), investigating the best surgical techniques for tumour associated epilepsy and the pioneering use of gene therapy for treating epilepsy.

Research value and impact

The Association of Medical Research Charities (AMRC) membership is the hallmark of quality research funding. It means that we fund high-quality, peer-reviewed work and that our research procedures are audited every five years in order to check that they meet the gold standard. For universities, government and other funding bodies, AMRC membership is a recognised indicator of quality, and it qualifies our grants for support from the government’s Charity Research Support Fund, which entitles universities to at least a 20% increase on our funding. As AMRC members, we are also provided with access to training alongside other research charities to share ideas and ensure we are operating best practice processes and procedures.

The research we fund will ultimately be of benefit to people with epilepsy as our understanding of the condition grows. Often the research we fund is the first step in a long journey to developing new treatments. One way we gauge the success of these early stage projects is by assessing the level of funding they subsequently secure from other funders to progress the work.

We closely monitor the impact of our grants to ensure that donations support research of the highest quality. We do this via a reporting platform called ‘Researchfish’, which is used by a growing network of funding bodies and universities in the UK and Europe. Researchfish enables our researchers to tell us, in detail, about where their findings have been disseminated and the impact they might have on future epilepsy research, scientists’ careers and, most importantly, people with epilepsy.

In the last five years we have invested over **£4.2 million** on research grants and these have leveraged a further **£24.5 million** in follow-on funding from other sources. Therefore, every pound invested by Epilepsy Research UK has generated a further **£5.82** for epilepsy research. This investment in epilepsy research demonstrates our ability to identify innovative research at an early stage that will

ultimately benefit people with epilepsy.

Another indicator of the quality of the research we fund is the number of publications that arise from the work. A total of 254 journal publications have resulted from Epilepsy Research UK grants during the 2010 – 2021 period, over 40 of which were in high impact journals such as Brain, Nature or Journal of Physiology. Further evidence of the quality of the work we fund is the number of citations these publications have achieved (i.e. the number of times the publications have been referred to by other researchers in their own work). In this case our 254 publications have been cited nearly 10,000 times.

Fundraising performance in 2020/21

The overall incoming resources from fundraising and trading activities during 2020/21 were £1,128,903 a drop in income of 47% compared to the previous year due to the global pandemic. Legacy income in the year was £423,737. We are aware of considerable delays in processing probate as advised by Smee and Ford but note this level of reserves is in keeping with traditional legacy income figures prior to the exceptional levels received in 2018 and 2019. Given the highly unpredictable nature of legacies, the Board has taken the decision to phase the research grant allocations to ensure we have a secure grant round for the next few years. This funding has also enabled the board to consider investment in a strategic opportunity.

Income from charitable trusts was £ 89,324, a decrease on 2019/20 of £11,075. Income from donations, events, community fundraising and Christmas card sales at £16,495 was a decrease of 42% from 2019-20. There is a significant drop in income relating to Christmas Cards due to the non payment of card sales from Cards for Good Causes.

Our fundraising approach

Last year, 92% % of our funding came from our community of supporters and this year, despite, the restrictions imposed by the global pandemic,

our supporters went above and beyond to continue with fundraising activities whenever possible. We greatly appreciate and recognise the importance and value of the relationship and work hard to ensure that our supporters are satisfied with the way the organisation both raises and spends its funds. However, we are mindful of the need to ensure that we develop our approach to securing additional, sustainable sources of income.

Many of our supporters take part in events to raise money through sponsorship. Whilst a considerable number organise places and events themselves, we do offer a range of “places” and opportunities to take part in challenge events that involve commercial third parties and this year these challenges moved to virtual events wherever possible. We have clear written contracts with these suppliers and there is full transparency of the costs involved. We employ, on a freelance basis, a trusts and foundations fundraiser for one day per week. This use of specialist support has proved to be cost effective.

We are registered with the Fundraising Regulator and work to ensure that all our fundraising is carried out to recognised standards. We do not directly fundraise or market to individuals who have not signed up as supporters or agreed to receive mail from the charity with news, information and fundraising opportunities. We have a clear set of guidelines for people who fundraise on our behalf and these are sent to and agreed by the fundraiser in advance of any activity.

We have had no complaints about our fundraising approach in the past year. Our fundraising is “light touch” rather than being intrusive or pressuring and we feel that this is appreciated by our supporters and donors.

General Data Protection Regulation (GDPR)

We undertake regular reviews of our systems, processes and data to ensure we are GDPR compliant.

As we moved to home working mid-March 2020 due to COVID-19, we developed a plan to ensure we remained compliant. As part of this plan we worked with our external IT provider to install VPN licenses to safeguard access to our donor database for the four people that required access. All post was diverted to the Chief Executive’s home which was then stored in a fireproof, locked safe until the CAN offices reopened.

Financial review

In 2020-21 our overall incoming resources were £1,226,279 and the costs of raising funds were £158,935 leaving £1,067,344 available for charitable activities. This was a reduction in net income of £989,289 compared to the previous year. The total spent on charitable activities was £1,839,714.

In the previous two years we were fortunate in receiving exceptional levels of legacy income. The legacy income budget for the year was for a more modest level, however the actual income of £423,737 fell short of the budget by £226,000. The Covid pandemic impacted significantly on income from fundraising events, however other donations compensated for the reduction. The 2018 level of legacy income enabled a designated research fund to be put aside to be utilised over subsequent years to deliver the development of the research strategy. By utilising the designated research fund we were able to award grants in 2021 of £1,320,966 a similar level to 2020. It is envisaged the impact of the Covid pandemic will influence income over the next couple of years and the designated research fund at 31 March 2021 will be utilised to try to maintain research grants at a similar level for the foreseeable future.

Bank balances of £3,399,537 are held for ongoing and future grant commitments and day-to-day liabilities. The trustees, having regard to the liquidity requirements of research grants awarded, need to ensure that funds are available to meet our commitments.

Specific investment powers of the trustees

The trustees, having regard to the liquidity requirements of research grants awarded, have kept available funds. Due to wider economic circumstances deposit rates have been depressed. Mindful of the low returns, the trustees placed some funds in medium and long term investments in 2019. Income from investments performed well and there was an unrealised gain on investment value in the year of £253,089.

Structure, governance and management

Governing document

Epilepsy Research UK (ERUK) is a charitable company limited by guarantee, incorporated (as Epilepsy Research Foundation) on 21st August 2003 and registered as a charity on 30th October 2003. The company is governed by its Memorandum and Articles of Association. On 22nd March 2007, The Memorandum and Articles of Association were amended by a special resolution to change the name of the company from Epilepsy Research Foundation to Epilepsy Research UK (as part of the merger process with the Fund for Epilepsy) and the company was registered with Companies House under this name on 30th March 2007. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

Appointment of trustees

As set out in the Articles of Association the trustees are appointed by the Board of Trustees. The Articles of Association provide for a minimum of 7 and a maximum of 16 trustees. At each Annual General Meeting one third of the trustees must put themselves forward for reappointment. The Board takes account of the skills and experience of its members when seeking to recruit new trustees and aims to recruit at least one new trustee each year. New trustees are selected as a result of nomination from members of the Board and through open advertisement.

Trustee induction and training

Following a governance review undertaken by Cass Business School last year, Epilepsy Research UK will aim to standardise its induction process for new trustees, so each new trustee receives a job description outlining a trustee’s responsibilities and is briefed by on the history, structure and ambitions of Epilepsy Research UK and financial responsibilities. New trustees also receive the Charity Commission publication The Essential Trustee. Trustees are encouraged to attend appropriate external training events that will develop their contribution to the governance of Epilepsy Research UK.

Organisation

The activities of Epilepsy Research UK are governed by the Board of Trustees, all of whom are Directors. The Board meets four times per year and devolves responsibility for overseeing the day-to-day running of the organisation to the Supervisory Committee comprising the Chairman, Honorary Treasurer, two other trustees and the Chief Executive. The Chief Executive is appointed by the trustees to manage the day-to-day operations of the charity.

Related parties

To assist the trustees in the selection and monitoring of research grants, Epilepsy Research UK has a Scientific Advisory Committee (SAC) which is composed of leading epilepsy experts and experts by experience. Membership of the SAC is by invitation.

Pay policy for senior staff

The directors, who are the Charity’s Trustees, and the Chief Executive comprise the key management personnel of the charity in charge of directing, controlling, running and operating the Charity on a day-to-day basis. All directors give of their time freely and no director received remuneration in the year. Details of directors’ expenses and related party transactions are disclosed in note 10 to the accounts. The Management Committee, excluding the Chief Executive, review employee pay on an annual basis

considering performance against objectives set and the retail price index. The pay of the Chief Executive is reviewed annually and normally increased in accordance with average earnings and by reference to that of Chief Executives of charities of similar size.

Discussions with other parties

As part of the merger with the Fund for Epilepsy in March 2007, two companies, Epilepsy Research Foundation Ltd and Fund for Epilepsy Ltd, were incorporated to protect these names, with Epilepsy Research UK as sole member. On a regular basis staff and trustees meet representatives of other charities and specialists in the field of epilepsy.

Risk management and disclosure

The Trustees view the strategic management of risk as an integral part of supporting effective planning and evaluation of its activities. Risk management is focused on risks associated with delivering our strategy and the 2021-22 business plan, with identified risks embedded in our strategic and operational processes. Governance of the Charity’s risk management ultimately sits with the Board of Trustees.

Our risk management approach details the structures and processes that have been put in place, and the key roles and responsibilities for successful risk management. In order to manage these risks, there are a number of controls and mitigations in place including (but not limited to):

- 1. Business plan and budget which has regular Board of Trustees oversight
- 2. Financial controls and policies (such as reserves, investment policies and ethical fundraising)
- 3. Disaster recovery and business continuity planning
- 4. Strategic partnership work.

There are three key strategic risks which cover both external and internal risks:

- Risk 1: Potential impact on community fundraising as a result of Coronavirus.
- Risk 2: Inadequate senior staff and staffing levels to support delivery of strategic objectives
- Risk 3: Legacy income fails to achieve target budget

The Board of Trustees are satisfied that the major risks have been identified and processes for addressing are in place. It is recognised that any control systems can only provide reasonable but not absolute assurance that major risks have been adequately managed. Overall, we are confident our risk position remains within acceptable levels. Key financial and non-financial risks are monitored throughout the year and reported to the Trustees on a quarterly basis.

Reserves policy

The Charity’s reserves policy focuses on the level of “free reserves”. Free reserves exclude restricted funds and designated funds. The recommended free reserves level is calculated annually in advance of the budget process on the basis of the financial impact of the current risks facing the charity and is reviewed annually by the trustees. The Charity seeks to maintain free reserves to manage the risks to which the Charity is exposed in the course of its business, including, but not limited to, safeguarding against the volatility of voluntary income. The trustees consider that in order to meet these needs, and to operate effectively, the Charity needs reserves of around £900,000. Designated research funds at 31 March 2021 are £1,043,000 which will enable the charity to focus on a sustainable level of research grants supporting the refreshed strategy.

Statement of trustees’ responsibilities

The charity trustees (who are also the directors of Epilepsy Research UK for the purposes of company law) are responsible for preparing a trustees’ annual report and financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the charity trustees to prepare financial statements for each year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources including the income and expenditure of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently
- observe the methods and principles in the applicable Charity SORP
- make judgements and estimates that are reasonable and prudent
- state whether applicable accounting standards have been followed
- prepare financial statements on a ‘going concern’ basis unless it is inappropriate to presume that the charitable company will continue in business

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to 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.

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

Statement as to disclosure of information to auditors

In so far as the trustees are aware at the time of approving our trustees’ annual report:

- there is no relevant information, being information needed by the auditor in connection with preparing their report, of which the auditor is unaware, and
- the trustees having made enquiries of fellow directors and the company’s auditor that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a director in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

By order of the Board of Trustees

Professor Matthew Walker
Chair, Board of Trustees

Report of the independent auditors to the trustees of Epilepsy Research UK

We have audited the financial statements of Epilepsy Research UK (the Charity) for the year ended 31st March 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement, 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 Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the Charity’s trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the Charity’s trustees 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 anyone other than the Charity’s trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the Charity’s affairs as at 31st March 2021 and of its

- income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006

Basis of 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 Charity 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

We have nothing to report in respect of the following matters in relation to which the ISA (UK) requires us to report to you where:

The trustees’ use of the going concern basis of accounting in the preparation is not appropriate, or

the trustees’ have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the Charity’s ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our auditor’s report thereon. 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 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.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees’ Annual Report (including the Strategic Report).

We have nothing to report in respect of the following matters in relation to which the Charities Act 2011 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;
- the financial statements are not in agreement with the accounting records and returns;
- we have not received all the information and explanations we require for our audit;
- the directors were not entitled to take advantage of the small companies exemption from the requirement to prepare a strategic report.

Responsibilities of trustees

As explained more fully in the Trustees’ Responsibilities Statement, set out on page 36, the trustees 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 they determine is necessary to enable the preparation of the 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 Charity’s ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the Charity or to cease operation, or have no realistic option but to do so.

Our responsibilities for the audit of the financial statements

The trustees have elected for the financial statements to be audited in accordance with the Charities Act 2011 rather than the Companies Act 2006. Accordingly, we have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulation made under section 154 of that Act.

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.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council’s website at www.frs.org/responsibilities. This description forms part of our auditor’s report.

A Davies ACA (Senior Statutory Auditor)
F A Magee & Company, Chartered Accountants & Statutory Auditors

Wimborne House, 4-6 Pump Lane, Hayes, UB3 3NB

Statement of Financial Activities
(including the Income & Expenditure Account)
for the year ended 31st March 2021

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £	Total Funds 2020 £
Income from:					
Donations and legacies	2	1,020,408	92,000	1,112,408	2,090,040
Charitable activities research grants not required	6	32,635	-	32,635	87,704
Other trading activities	3	16,495	-	16,495	28,598
Investments	4	64,741	-	64,741	48,752
Total Income		1,134,279	92,000	1,226,279	2,255,094
Expenditure on:					
Raising Funds	5	158,935	-	158,935	198,461
Charitable Activities:					
Research grants committed	6	1,297,966	23,000	1,320,966	1,340,440
Other research activities	7	518,148	600	518,748	530,939
Total Charitable Activities		1,816,114	23,600	1,839,714	1,871,379
Total Expenditure		1,975,049	23,600	1,998,649	2,069,840
Net unrealised Gains / (Losses) on investments		253,089	-	253,089	(67,948)
Net Income/(Expenditure) for the year		(587,681)	68,400	(519,281)	117,306
Transfers between funds	16	48,000	(48,000)	-	-
Net (Decrease)/Increase in Funds for the year		(539,681)	20,400	(519,281)	117,306
Reconciliation of Funds:					
Total funds brought forward on 1 April 2020		2,483,224	6,960	2,490,184	2,372,878
Total funds carried forward at 31 March 2021	15, 16	1,943,543	27,360	1,970,903	2,490,184

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing activities.

The notes on pages 43 to 56 form part of these financial statements.

Balance Sheet at 31st March 2021

	Note	2021 £	2020 £
Fixed Assets	11	<u>2,311,606</u>	<u>2,016,232</u>
		2,311,606	2,016,232
Current Assets			
Debtors	12	608,632	1,131,994
Cash at bank and in hand	13	<u>3,399,537</u>	<u>2,962,503</u>
		4,008,169	4,094,497
Creditors: Amounts falling due within one year	14	(1,956,691)	(1,553,440)
Net Current Assets		<u>2,051,478</u>	<u>2,541,057</u>
Total Assets less Current Liabilities		4,363,084	4,557,289
Creditors: Amounts falling due within one year	14	<u>(2,392,181)</u>	<u>(2,067,105)</u>
Total Net Assets		<u>1,970,903</u>	<u>2,490,184</u>
The Funds of the Charity			
Unrestricted Funds			
Designated Funds	15	1,042,684	1,494,579
General Fund	15	<u>900,859</u>	<u>988,645</u>
		1,943,543	2483,224
Restricted Funds	16	<u>27,360</u>	<u>6,960</u>
Total Charity Funds		<u>1,970,903</u>	<u>2,490,184</u>

The financial statements were approved by the Board of Trustees on 23rd June 2021 and signed on its behalf by:

Prof Matthew Walker
Chair

Judith Spencer-Gregson FCA
Treasurer

The notes on pages 43 to 56 form part of these financial statements.

Statement of Cash Flows for the year ended 31st March 2021

	Note	2021 £	2020 £
Cash Inflow from Operating Activities	19	<u>414,578</u>	<u>568,330</u>
Cash Flows from Investing Activities			
Sale of investments		472,588	-
Net purchase of investments		(469,964)	(1,000,000)
Income reinvested		(44,245)	(27,970)
Dividends and interest received		64,077	48,752
Net Cash Inflow/(Outflow) Investing Activities		<u>22,456</u>	<u>(979,218)</u>
Increase/(Decrease) in Cash and Cash Equivalents in the Year		<u>437,034</u>	<u>(410,888)</u>
Cash and Cash Equivalents at the Beginning of the Year		<u>2,962,503</u>	<u>3,373,391</u>
Cash and Cash Equivalents at the End of the Year		<u>3,399,537</u>	<u>2,962,503</u>

Notes
forming part of the financial statements

1 Accounting policies

The charity is a company limited by guarantee and has no share capital. In the event of the charity being wound up the liability in respect of the guarantee is limited to £1 per member of the charity.

a) Basis of preparation

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 SORP (FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Epilepsy Research UK 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 accounting policy note(s).

Reconciliation with previous Generally Accepted Accounting Practice: in preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS 102 and the Charities SORP FRS 102 the restatement of comparative items was required.

b) Fixed assets

Investments: The charity holds investments and these have been valued at market value as at the year end.

Office equipment: The trustees consider the provision of all office equipment to be part of the running costs of the organisation and it is written off in the year of purchase.

c) Incoming resources

Voluntary income and donations are taken into the accounts when received. The income from fundraising ventures is shown gross, with the associated costs included in fundraising costs. Legacy income is included in the Statement of Financial Activities to the extent of cash received or a clear indication regarding amounts receivable has been given by executors. No endowments have been received in the period.

d) Resources expended

All expenses are accounted for on an accruals basis. Wherever possible costs are allocated directly to the appropriate activity; other costs common to all activities are apportioned between those activities based on the proportion of staff time spent during each year in connection with each activity (see note 8).

Fundraising expenditure comprises costs incurred in asking people and organisations to donate to the charity’s work. This includes the cost of advertising for donations and the staging of special fundraising events.

Expenditure incurred in connection with the specific objects of the charity is included under the heading Charitable Activities.

e) Donated services

Donated services are recognised as income when the receipt of economic benefit from the use by the charity of the item is probable and that

economic benefit can be measured reliably.

f) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably

g) Grants committed

All individual grants are fully provided for in the accounts in the year in which they are authorised by the trustees whether they are for short-term projects or for those extending over a year or more. All current grants are of a maximum duration of 3 years and all grants are covered by our cash balances and deposits.

h) Pension costs

The charity operates a defined contribution scheme with a charity contribution of 5% of salary costs. The cost of providing pensions for employees is charged to the Statement of Financial Activities in the year in which the contributions are paid.

i) Value Added Tax (VAT)

VAT is not recovered by the charity and is included in relevant costs in the Statement of Financial Activities.

j) Operating leases

The charity has no current operating leases.

k) Funds

General funds are unrestricted funds which are available for use at the discretion of the trustees in furtherance of the general objects of the charity and have not been designated for other purposes.

Designated funds comprise funds which have been set aside by the trustees for particular purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund.

l) Taxation

The charity is exempt from tax on income and gains falling within Part 10 of the Income Tax Act 2007 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable activities.

2 Donations and Legacies

	Unrestricted Funds £	Restricted Funds £	Total 2021 £	Total 2020 £
Charitable trusts	30,324	59,000	89,324	100,399
In memoriam donations	73,289	-	73,289	95,353
Other donations	350,627	23,000	373,627	287,569
Fundraising events	152,431	-	152,431	294,008
Legacies	413,737	10,000	423,737	1,312,711
	<u>1,020,408</u>	<u>92,000</u>	<u>1,112,408</u>	<u>2,090,040</u>

Donations and Legacies 2020

	Unrestricted Funds £	Restricted Funds £	Total 2020 £
Charitable trusts	83,399	17,000	100,399
In memoriam donations	95,353	-	95,353
Other donations	287,569	-	287,569
Fundraising events	294,008	-	294,008
Legacies	1,312,711	-	1,312,711
	<u>2,073,040</u>	<u>17,000</u>	<u>2,090,040</u>

Income from fundraising events arises from events organised by the charity and its supporters. Online advertising to the value of £72,630 (2020 £82,604) was donated as a Gift in Kind and this amount is included in “Other donations”.

Legacies: The charity’s policy is to accrue into the accounts all legacies notified during the year where there is sufficient evidence to provide the necessary certainty that the legacy will be received and the value of the incoming resources can be measured with sufficient reliability. The charity has been bequeathed a property that is subject to a life tenancy interest held by the legator’s widow. At the time of the legator’s death in 2002, the property was valued at £95,000.

3 Other Trading Activities

	Unrestricted Funds £	Restricted Funds £	Total 2021 £	Unrestricted Total 2020 £
Sale of Christmas cards	<u>16,495</u>	<u>-</u>	<u>16,495</u>	<u>28,598</u>

4 Investment Income

	Unrestricted Funds £	Restricted Funds £	Total 2021 £	Unrestricted Total 2020 £
Realised gain on investments	664	-	664	-
Dividend & investment income	58,536	-	58,536	37,587
Interest on deposits	5,541	-	5,541	11,165
	<u>64,741</u>	<u>-</u>	<u>64,741</u>	<u>48,752</u>

5 Costs of generating funds

	Unrestricted Funds £	Restricted Funds £	Total 2021 £	Unrestricted Total 2020 £
Direct fundraising	53,891	-	53,891	99,517
Staff costs	82,412	-	82,412	70,491
Other overhead expenses	16,884	-	16,884	22,985
Governance costs	5,748	-	5,748	5,468
	<u>158,935</u>	<u>-</u>	<u>158,935</u>	<u>198,461</u>

6 Research Grants Committed

	2021 £	2020 £
Committed as at 31 March 2020	3,582,237	2,990,146
Authorised during year (see Trustees’ report)	1,320,966	1,340,440
No longer required	(32,635)	(87,704)
Paid in year	(572,289)	(660,645)
Committed as at 31 March 2021	4,298,279	3,582,237

Authorised grants represent awards made to research institutions to further the understanding and treatment of epilepsy. An overview of the awards are set out in the Trustees report on pages 10-19. Details of all grants awarded are available on the website: www.epilepsyresearch.org.uk. Research grants no longer required relates to projects that were completed without the total original grant being spent.

7 Other Research Activities

	Unrestricted Funds £	Restricted Funds £	Total 2021 £	Total 2020 £
Staff costs	302,512	-	302,512	246,513
Scientific workshop	-	-	-	-
Research meetings, events & activities	5,020	-	5,020	18,503
Research prizes	-	600	600	1,374
Research dissemination & communication	124,904	-	124,904	165,907
Overhead expenses	64,611	-	64,611	80,285
Governance costs	21,101	-	21,101	18,357
	518,148	600	518,748	530,939

Other Research Activities 2020

	Unrestricted Funds £	Restricted Funds £	Total 2020 £
Staff costs	246,513	-	246,513
Scientific workshop	-	-	-
Research meetings, events & activities	18,503	-	18,503
Research prizes	-	1,374	1,374
Research dissemination & communication	165,907	-	165,907
Overhead expenses	80,285	-	80,285
Governance costs	18,357	-	18,357
	529,565	1,374	530,939

8 Support and Governance costs

	Support Costs £	Governance Costs £	Total 2021 £	Total 2020 £
Staff costs	-	9,333	9,333	8,313
Other staff costs	13,400	-	13,400	-
Office rent & facilities	31,758	-	31,758	32,780
Office running costs	20,072	-	20,072	31,389
IT & bank charges	16,265	-	16,265	28,983
Investment fees	-	18,924	18,924	10,118
Audit	-	4,600	4,600	4,620
Trustee meetings & expenses	-	-	-	2,327
Legal & professional fees	-	3,325	3,325	8,565
	81,495	36,182	117,677	127,095

Basis of Allocation

Allocated to fundraising costs	16,884	10,415	27,299	23.20%
Allocated to charitable activities	64,611	25,767	90,378	76.80%
	81,495	36,182	117,677	100%

Support and Governance costs 2020

	Support Costs £	Governance Costs £	Total 2020 £
Staff costs	-	8,313	8,313
Office rent and facilities	32,780	-	32,780
Office running costs	31,389	-	31,389
IT and bank charges	28,983	-	28,983
Investment fees	10,118	-	10,118
Audit	-	4,620	4,620
Trustee meetings & expenses	-	2,327	2,327
Legal & professional fees	-	8,565	8,565
	103,270	23,825	127,095

Basis of Allocation

Allocated to fundraising costs	22,985	5,468	28,453	22.95%
Allocated to charitable activities	80,285	18,357	98,642	77.05%
	103,270	23,825	127,095	100%

9 Net incoming resources are after charging the following:

	2021 £	2020 £
Auditors’ remuneration	4,600	4,620
Payroll fees	1,200	1,136

10 Staff Costs

	2021 £	2020 £
Salaries	338,769	287,095
Social security costs	32,867	26,502
Pension costs	13,287	11,720
	<u>384,923</u>	<u>325,317</u>

One employee earned between £70,001 and £80,000 (2020/21)

The average number of full-time equivalent employees (including casual part-time staff) during the year was as follows:

	2021	2020
Charitable activities	6.01	5.7
Fundraising	1.79	1.8
Governance	0.10	0.1
	<u>7.90</u>	<u>7.6</u>

The Trustees do not receive any remuneration for their duties and during the year no Trustees received expenses for travelling to meetings (2020: £1,459 - 1 Trustee). No trustee or persons with family or business connections with Trustees has received remuneration directly or indirectly from the charity. The charity includes Trustees’ Liability Insurance in its combined insurance policy.

11 Investments

	2021 £	2020 £
Market value 1 April 2020	2,016,232	1,056,210
Acquisitions	469,964	1,000,000
Sales	(472,588)	-
Investment charges	(18,924)	(9,617)
Income reinvested	63,169	37,587
	<u>2,057,853</u>	<u>2,084,180</u>
Net gain/(loss) realised	664	-
Net gain/(loss) unrealised	253,089	(67,948)
Market value 31 March 2021	<u>2,311,606</u>	<u>2,016,232</u>

Analysis of investments

Quoted Charity Common Investment funds	2,294,209	1,306,439
Medium and long term	17,397	709,793
Cash on deposit	<u>2,311,606</u>	<u>2,016,232</u>

12 Debtors

	2021 £	2020 £
Gift Aid recoverable	20,831	11,491
Prepayments & accrued income	587,801	1,120,503
	<u>608,632</u>	<u>1,131,994</u>

Debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

13 Cash Movements

	Cash Deposits £	Cash at Bank £	Total 2021 £
Balance at 31 March 2020	2,658,130	304,373	2,962,503
Cash inflow	265,028	172,006	437,034
Balance as at 31 March 2021	2,923,158	476,379	3,399,537

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of less than twelve months from the balance sheet date.

Cash Movements 2020

	Cash Deposits £	Cash at Bank £	Total 2020 £
Balance at 31 March 2019	1,852,819	1,520,572	3,373,391
Cash inflow/(outflow)	805,311	(1,216,199)	(410,888)
Balance as at 31 March 2020	2,658,130	304,373	2,962,503

14 Liabilities

	2021 £	2020 £
Research grants not yet claimed	1,906,098	1,515,132
Accruals	16,672	9,075
Other creditors	33,921	29,233
Due within 12 months	1,956,691	1,553,440
Research grants due after 12 months	2,392,181	2,067,105
	4,348,872	3,620,545

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

15 Unrestricted Funds

These represent amounts expendable at the discretion of the Trustees. The balance of the charity’s resources represent free reserves which are not yet current assets retained to protect the work of the charity in the event of unforeseen and significant changes in its financial position. The designated fund represents money set aside by the Trustees for future research grants.

	Designated Research Fund £	General Fund £	Total 2021 £
Balance as at 1 April 2020	1,494,579	988,645	2,483,224
Net outflow of resources	-	(539,681)	(539,681)
Transfer between funds	(451,895)	451,895	-
Balance as at 31 March 2021	1,042,684	900,859	1,943,543

Unrestricted Funds 2020

	Designated Research Fund £	General Fund £	Total 2020 £
Balance as at 1 April 2019	1,690,000	654,544	2,344,544
Net incoming resources	-	138,680	138,680
Transfer between funds	(195,421)	195,421	-
Balance as at 31 March 2020	1,494,579	988,645	2,483,224

16 Restricted Funds

	1 April 2020 £	Incoming Resources £	Resources Expended £	Transfer to Unrestricted Funds £	31 March 2021 £
Research Grants	-	71,000	(23,000)	(48,000)	-
Shape Network	-	21,000	-	-	21,000
Intercapital prize	6,960	-	(600)	-	6,360
	<u>6,960</u>	<u>92,000</u>	<u>(23,600)</u>	<u>(48,000)</u>	<u>27,360</u>

Restricted income for research grants relates to income of £48,000 to support a grant committed in the previous financial year for Professor Mike Cousin and is shown as a transfer between restricted and unrestricted funds. Further income of £23,000 was received towards a joint project awarded this year to Professor Markus Reuber. During the year we launched the Shape Network, where expenditure will be incurred during 2021-22.

Restricted Funds 2020

	1 April 2019 £	Incoming Resources £	Resources Expended £	31 March 2020 £
Research Grants	-	17,000	(17,000)	-
Intercapital prize	28,334	-	(21,374)	6,960
	<u>29,995</u>	<u>17,000</u>	<u>(38,374)</u>	<u>6,960</u>

17 Analysis of Net Assets between Funds

	Unrestricted Funds £	Restricted Funds £	Total Funds £
Total Assets	6,292,415	27,360	6,319,775
Current liabilities	(1,956,691)	-	(1,956,691)
Creditors falling due after more than 1 year	(2,392,181)	-	(2,392,181)
	<u>1,943,543</u>	<u>27,360</u>	<u>1,970,903</u>

Analysis of Net Assets between Funds 2020

	Unrestricted Funds £	Restricted Funds £	Total Funds £
Total Assets	6,103,769	6,960	6,110,729
Current liabilities	(1,553,440)	-	(1,553,440)
Creditors falling due after more than 1 year	(2,067,105)	-	(2,067,105)
	<u>2,483,224</u>	<u>6,960</u>	<u>2,490,184</u>

18 Related Party Transactions

The field of epilepsy research is highly specialised and for Epilepsy Research UK to function effectively it is vital that leading practioners are represented on our trustee board and the Scientific Advisory Committee (SAC). Trustees and SAC members are eligible to submit funding applications to Epilepsy Research UK, but they must declare any conflicts of interest concerning grant applications and are excluded from any discussion regarding the merits of such applications. Grants awarded in March 2021 included £250,000 to University of Newcastle where Dr Rhys Thomas has an interest and £250,000 to University of Edinburgh where Professor Mike Cousin has an interest. Both awards were to establish a PhD hub and not a direct grant to the Trustee.

In the year ended 31 March 2020 payments of £346 were made to University College London towards a grant to Professor Stephanie Schorge. This grant was approved prior to her appointment as a trustee. Grants awarded in March 2020 included £188,666 to University College, London for a grant to Professor Matthew Walker, and £154,537 to University of Edinburgh towards a grant to Professor Mike Cousin.

19 Reconciliation of Net Movement in Funds to Net Cash Flow from Operating Activities

	2021 £	2020 £
Net (outflow)/inflow in funds	(519,281)	117,306
Deduct Investment income shown in investing activities	(64,741)	(48,752)
Deduct investment gain/add (loss)	(253,089)	67,948
(Increase)/Decrease in debtors	523,362	(147,294)
Increase/ (Decrease) in creditors due within 1 year	403,251	(223,851)
Increase/(Decrease) in creditors due after more than 1 year	325,076	802,973
Net cash used in operating activities	<u>414,578</u>	<u>568,330</u>

21 Statement of Financial Activity for the year ended 31 March 2020 (prior year)
(Including the Income & Expenditure Account)

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Income from:				
Donations and legacies	2	2,073,040	17,000	2,090,040
Charitable activities research grants not required	6	87,704	-	87,704
Other trading activities	3	28,598	-	28,598
Investments	4	48,752	-	48,752
Total Income		<u>2,238,094</u>	<u>17,000</u>	<u>2,255,094</u>
Expenditure on:				
Raising Funds	5	<u>198,461</u>	<u>-</u>	<u>198,461</u>
Charitable Activities:				
Research grants committed	6	1,320,440	20,000	1,340,440
Other charitable activities	7	529,565	1,374	530,939
Total Charitable Activities		<u>1,850,005</u>	<u>21,374</u>	<u>1,871,379</u>
Total Expenditure		<u>2,048,466</u>	<u>21,374</u>	<u>2,069,840</u>
Net Gain/(Loss) on investments		<u>(67,948)</u>	<u>-</u>	<u>(67,948)</u>
Net Income/(Expenditure) for the year		121,680	(4,374)	117,306
Transfers between funds	16	<u>17,000</u>	<u>(17,000)</u>	<u>-</u>
Net Movement in Funds for the year		138,680	(21,374)	117,306
Reconciliation of Funds:				
Total funds brought forward on 1 April 2019		<u>2,344,544</u>	<u>28,334</u>	<u>2,372,878</u>
Total funds carried forward at 31 March 2020	15,16	<u>2,483,224</u>	<u>6,960</u>	<u>2,490,184</u>

A man with a beard, wearing a dark beanie and a dark jacket, is looking out of a car window. The background shows a brick building with windows and a blue sky.

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