

EPILEPSY RESEARCH - ARE WE AT A TIPPING POINT?

Annual Review 2021/22



20
22

LIFE **CHANGING**
LIFE **SAVING** RESEARCH

Charlie Steward is a Genome Scientist, epilepsy campaigner and advocate. Pushing forward research into epilepsy is not just a professional motivation for Charlie, but a personal one. Both of Charlie’s children are living with severe neurological conditions and one of them was diagnosed with a rare type of epilepsy at eight months, called West syndrome. He passionately wants to see research deliver for patients and their families.

“It takes a multi-disciplinary team to deliver the best possible care for my children. The same applies to research. Everyone needs to work together to accelerate the translation of research from the lab to the bedside. It’s also essential the voice of the patient, family and carers is at the centre of all our collaborations.”



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tipping point

noun: tipping point; plural noun: tipping points

the point at which a series of small changes or incidents becomes significant enough to cause a larger, more important change.

FOR TOO LONG THE SCALES HAVE BEEN WEIGHTED AGAINST US

Weighted against every one of the **600,000** adults, children and babies who are living with epilepsy in the UK. Weighted against the **180,000** people who have no other option than to live under the constant and uncontrolled threat of seizures. And, most devastatingly of all, weighted against the **21** people who lose their lives every week to epilepsy-related deaths.

The scales have also been weighted against the research community. Hampered by decades of underinvestment, large gaps in evidence and knowledge, too few opportunities for patient involvement and a lack of national strategy and long-term vision from the government.

THE YEAR THE SCALES STARTED TO TIP

As the only UK charity dedicated to driving and enabling research into epilepsy, we have contributed to significant advances in the treatment and care provided to people living with epilepsy. In 2022 we provided £1.5 million in new grants – our largest single investment to date.

We are proud to have funded four Emerging Leader Fellowship Awards spanning the breadth of research into epilepsy, including basic science, translational research, clinical research and Big Data. We also awarded five Endeavour Project Grants which aim to underpin future research into epilepsy and associated conditions, and change clinical policy and practice.

As well as funding, driving and enabling research, we spent the year building our evidence base and understanding of the priority areas people want to see addressed by research. We successfully brought the epilepsy community together for a common purpose through funding and leading a UK Epilepsy Priority Setting Partnership (PSP) with the James Lind Alliance and NHR. This project involved people affected by epilepsy, patient organisations and leading clinicians and researchers from across the UK.

We have also further developed our Shape Network – now the largest ever community of research-interested people affected by epilepsy. By the end of the reporting period, this work will provide vital underpinning evidence to support and capitalise on policy shifts taking place in the coming year and help us to reach a **tipping point in epilepsy research**.



Over £1.5 million
invested in our 2022
Research Awards

A MESSAGE FROM OUR CHAIR & CEO

At the time of writing this report the World Health Organization has just approved the Intersectoral Global Action Plan on Epilepsy (IGAP). Strictly speaking the approval of IGAP in May falls outside of our reporting period of April 2021 – March 2022, but it's important to recognise its impact and how our work this past year will support the government in making epilepsy a priority.

We have always said it will take a global effort to halt epilepsy. Now, with the IGAP, governments around the world will be tasked with responding to the recommendations to bring about changes in both policy and practice for epilepsy. This development is significant. It's exciting. It's also long overdue.

Over two years ago we called out the huge inequity of epilepsy research funding in contrast to other, less prevalent neurological conditions through our #ALifeInterrupted campaign. Yes epilepsy is complex, but it's also treatable. As the only UK charity exclusively dedicated to epilepsy research, we're proud of the £1.5 million of new grants we provided to researchers this past year. This is our largest ever single investment in research and includes four Emerging Leader Fellowship Awards and five Endeavour Project Grants.

While it's important we continue to fund these groundbreaking projects, we need to go further to tip the balance. These projects are helping to push forward the discovery of future treatments, but on its own it's not enough. There's a limit on

how much we can realistically expect to raise, and therefore a limit on how much we can realistically expect to fund.

Research into epilepsy needs to be radically scaled up. When we developed our Going Further strategy in 2020 we focused on how we could capacity build epilepsy research and create an environment for research to flourish.

“**Alongside supporting and funding research, we have focused our attentions on the other ingredients needed to push forward epilepsy research in the UK.**”

In 2021/22 we launched a Priority Setting Partnership with the James Lind Alliance to identify and prioritise the top ten unanswered research questions. We involved the whole community, people affected by epilepsy, clinicians, researchers and epilepsy and associated condition patient groups. Due to be published in the autumn, the UK Epilepsy PSP top ten will provide jointly agreed research priorities that will enable research to be focused on what will make the biggest difference to the epilepsy community.

This is a huge step forward in reducing the evidence and knowledge gaps that have hampered our ability to make a compelling case of support to the government, who has not so far prioritised epilepsy. This is despite it being one of the most prevalent, serious neurological condition in the world.

Alongside building an evidence base, we also continued our work in building a community of people committed and mobilised to support research. We set out to create the largest patient population of people affected by epilepsy who want to get involved in research. We're delighted to say that our Shape Network are now actively involved and working together with epilepsy researchers.

Our 2022 grant application assessment process, managed by our Scientific Advisory Committee, this year rolled out a new initiative, the Shape Network Applications Clinics which brought together people affected by epilepsy and researchers. We would like to thank all network members for being part of this process. Increasing the involvement of people with lived experience is a key part of our work and it was heartening to see this vision realised.

With the new interest and focus on epilepsy, the timing of the UK Epilepsy PSP and Shape Network couldn't have been better. The UK Epilepsy PSP, our Shape Network, the new NICE Guidelines, and the IGAP, have created an opportunity to radically advance epilepsy research.

The bottom line is, we are now at a tipping point and the continued efforts of all those involved are beginning to tip the scales in our favour.

We finally have an alignment between evidence, policy and a collective global ambition for change. It's an exciting time for epilepsy research.

What's our role in this? During 2021/22 we developed plans to leverage the momentum we now have. Our #Every1EndingEpilepsy programme will help drive the urgently needed systematic and strategic change. Through this programme, we will provide a fully costed road map to the UK government to enable them to implement the recommendations from the IGAP. We will call on the government to invest £100 for each of the estimated 600,000 people living with epilepsy in the UK. That's £100 for every 1 in 100 – a £60 million accelerator fund.

As always, we want to thank our supporters for everything this past year. We know many of you have personally seen and experienced the devastation epilepsy can so often cause.

All the ingredients are now in place to radically accelerate progress in epilepsy research. We will ensure the epilepsy community, and especially those living with the condition, come together and have a driving seat in ensuring research finally delivers for them.

Thank you.



**Professor
Matthew Walker**
Chair of Trustees



Maxine Smeaton
Chief Executive

RESEARCH IN NUMBERS

52 research projects currently being funded by Epilepsy Research UK

£1.5m of research grants awarded this year

over 300 journal publications have resulted from Epilepsy Research UK grants during the 2009 - 2021 period

5,418 research priorities identified from the 2,014 responses from the UK Epilepsy Priority Setting Partnership

£5.3m invested in reseach grants by Epilepsy Research UK between 2017-2021



these grants have leveraged over **£31.4m** in follow-on funding from other sources



this means that for every pound invested by Epilepsy Research UK a further **£5.91** has been generated for epilepsy research

RESEARCH GRANTS IN 2022

This year we awarded £1.5m of research grants to investigate the underlying causes and mechanisms of epilepsy and drive innovations in treatment and prevention.

Summary of research grants awarded

PRINCIPAL INVESTIGATOR, INSTITUTION	TITLE	AMOUNT
Dr Kathryn Bush Newcastle University	Understanding epilepsy inequalities in the UK	£249,993
Dr Amol Bhandare University of Warwick	Investigating the role of microglia in drug-resistant seizures, sudden death and memory function in epilepsy	£249,570
Dr Faye McLeod Newcastle University	Exploring the mechanisms behind early onset genetic epilepsies using human brain tissue	£250,000
Dr Josphine Mayer University of Liverpool	Joint funding with Association of British Neurologist & Stroke Association: Exploring the link between seizures and cardiovascular health in the aging population	£88,470
Dr Karen Smillie University of Edinburgh	Causal relationship between activity-induced synapse sprouting and epileptogenesis	£149,994
Dr Rob Wykes University College London	The contribution of spreading depression (SD) to postictal generalised EEG suppression (PGES): Onset and recovery	£139,716
Dr Sukhvir Wright Aston University	Can we extinguish the seizures in FIRES?	£145,591
Dr Jonathan Lippiat University of Leeds	Evaluating the efficacy of potassium channel inhibitors in KCNT1-associated epileptic disorders	£141,236
Dr Sophie Adler University College London	Multi-centre Epilepsy Lesion Detection Project: a collaborative cohort for the analysis of focal epilepsies	£148,279
Dr Colin Reilly UCL, Great Ormond Street Institute of Child Health	Joint funding with Autistica – Autism and epilepsy : laying out the evidence	£10,000
Total grants awarded		£1,572,849

In addition, we are currently funding 42 other projects, approved in prior years, at institutes around the country. Examples of which include 13 PhD studentships across two Doctoral Training Centres in Newcastle and Edinburgh, as well as studies investigating ground-breaking gene therapy techniques to prevent seizures and novel neuroimaging studies to make bedside brain imaging a reality.



A YEAR IN RESEARCH

In 2022 we funded four Emerging Leader Fellowships and five Endeavour Projects to investigate the underlying causes and mechanisms of epilepsy and drive innovations in treatment and prevention.

Our investment means that nine new studies will be taking place across the country, involving over 30 researchers and collaborators. In total we are now funding 52 research projects nationally.

Our fellowship awards allow us to attract the best 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. In 2022 we awarded more fellowships than ever before.

OUR 2022 GRANT AWARDS

We are proud to announce we awarded over £1.5 million of research funding in our 2022 research awards – our largest single investment to date.

The funded research will take place in universities and hospitals across the country including the University of Edinburgh, University College London, the University of Warwick, Newcastle University, the University of Leeds and Aston University.

This investment means that 9 new studies will be taking place across the country involving over 30 researchers and collaborators.



EPILEPSY RESEARCH UK & ABN & STROKE ASSOCIATION CLINICAL RESEARCH TRAINING FELLOWSHIP



Dr Josephine Mayer
University of Liverpool
Exploring the link between seizures and cardiovascular health in the aging population

ENDEAVOUR PROJECT GRANT



Dr Jonathan Lippiat
University of Leeds
Evaluating the efficacy of potassium channel inhibitors in KCNT1-associated epileptic disorders

EMERGING LEADER FELLOWSHIP AWARD



Dr Amol Bhandare
University of Warwick
Investigating the role of microglia in drug-resistant seizures, sudden death and memory function in epilepsy

ENDEAVOUR PROJECT GRANT



Dr Sophie Adler
University College London
Multi-centre Epilepsy Lesion Detection Project: a collaborative cohort for the analysis of focal epilepsies

ENDEAVOUR PROJECT GRANT



Dr Rob Wykes
University College London
Improved understanding of the mechanisms and intervention strategies for a known risk factor for SUDEP

ENDEAVOUR PROJECT GRANT



Dr Sukhvir Wright
Aston University
Can we extinguish the seizures in FIRES?

ENDEAVOUR PROJECT GRANT



Dr Karen Smillie
Dr Daniela Ivanova, Co-investigator
University of Edinburgh
Impact of seizure-induced changes in nerve cell structure on epileptogenesis

EMERGING LEADER FELLOWSHIP AWARD



Dr Kathryn Bush
Newcastle University
Understanding epilepsy inequalities in the UK

EMERGING LEADER FELLOWSHIP AWARD



Dr Faye McLeod
Newcastle University
Exploring the mechanisms behind early onset genetic epilepsies using human brain tissue

To read more about each of the research projects, scan the QR code here. This research would not have been possible without the incredible efforts and generosity of you – our supporters. Thank you.



STRONGER TOGETHER - BUILDING COLLABORATIONS TO DRIVE IMPACT

In February 2022, we partnered with The Association of British Neurologists (ABN) and the Stroke Association to jointly award a Clinical Research Training Fellowship to Dr Josephine Mayer, based at the neuroscience research centre at the University of Liverpool.

EPILEPSY RESEARCH UK, ASSOCIATION OF BRITISH NEUROLOGISTS & STROKE ASSOCIATION
CLINICAL RESEARCH TRAINING FELLOWSHIP AWARD
EXPLORING THE LINK BETWEEN SEIZURES AND CARDIOVASCULAR HEALTH IN THE AGING POPULATION
Dr Josephine Mayer, University of Liverpool
£265,409 over 46 months



“Patients who develop unprovoked seizures later in life are at increased risk of subsequent stroke, but this relationship is not well understood. This study will investigate the health of blood vessels in the brain and heart in patients with late onset seizures, improving our understanding of the relationship between cardiovascular health and epilepsy. The results will guide future trials to improve care and long-term outcomes for these patients”

Dr Josephine Mayer

Dr Mayer’s research will explore the link between seizures and cardiovascular health in the ageing population. The project will also establish a patient registry to evaluate markers of poor vascular health, MRI brain imaging data and review the rate of stroke and heart disease at 12 months.

Due to the ageing population, the number of people experiencing late onset seizures and epilepsy is increasing. People who experience unprovoked seizures in adulthood are at increased risk of stroke, and it is not known whether this increased risk is due to untreated risk factors such as diabetes or high blood pressure or cardiovascular health.

The primary aim of this project is to assess the heart and brain blood vessel health in patients with late onset seizures. This study will improve our understanding of the relationship between cardiovascular health and epilepsy and improve our understanding of the relationship between cardiovascular risk factors and seizures in later life.



OUR RESEARCH DRIVING CHANGE TODAY

In April 2022, an article in The Sunday Times highlighted the devastating harm the drug sodium valproate has caused some women and their babies. According to the Cumberlege Report, at the time of the publication, an estimated 20,000 people in the UK had been affected by in-utero exposure to sodium valproate.



Dr Bromley’s research, funded by Epilepsy Research UK, provided the evidence that subsequently led to changes in policy and clinical practice outlined in the Cumberlege Report. It is now a requirement for all women with epilepsy to be informed of the risk of valproate and other anti-epileptic seizure medications during pregnancy. We know more needs to be done, but this work has greatly reduced the risk to countless babies of women with epilepsy.

“As an active member of the Valproate Stakeholders Network, I’ve seen first-hand how the combination of research and campaigning can bring about change in healthcare policy and in practice. Together we have the power to transform the lives of people. People like me.”

Faye Waddams is a campaigner and advocate for better information and advice for women with epilepsy.





FROM GRAINS OF SAND TO WEIGHTS

Every research project, every researcher dedicating their career to epilepsy, every new technological development, on their own act like a grain of sand, tipping the balance of the scales by contributing to our understanding of the disease.

But we know progress has been slow. For research to finally deliver for epilepsy, as it has for other conditions, we needed to find a way to turn those grains of sands into weights – to really start accelerating progress.

In 2022 we funded more research grants than ever before and continued our work on capacity-building the epilepsy research environment. But we went further. We began developing the building blocks to support greater investment in research by bringing the epilepsy, associated conditions and research communities together. By building strong, collaborative relationships and gathering the views and priorities of the entire epilepsy community we are gathering the evidence required to support policy changes currently in development.



TARGET ONE:
GATHERING EVIDENCE
TO DRIVE CHANGE



TARGET TWO:
CONNECTING RESEARCHERS
& PEOPLE AFFECTED BY
EPILEPSY



TARGET THREE:
STRONGER TOGETHER -
BUILDING PARTNERSHIPS
& COLLABORATIONS



Dr Faye McLeod
Newcastle University

TARGET ONE: GATHERING THE EVIDENCE TO DRIVE CHANGE

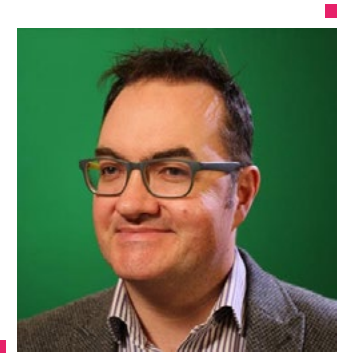
This year we funded and led a once-in-a-generation national survey – the UK Epilepsy Priority Setting Partnership. We involved the entire epilepsy community, from people affected by epilepsy to clinicians and researchers. In partnership with Autistica and Young Epilepsy, we commissioned and published an epilepsy and autism dossier in partnership. We also continued to promote the evidence of chronic underfunding in epilepsy research as part of the ‘ALifeInterrupted’ report and campaign.



UK EPILEPSY PRIORITY SETTING PARTNERSHIP

In November 2021 we launched a once in a generation national survey – the UK Epilepsy Priority Setting Partnership (PSP) in conjunction with the James Lind Alliance and NIHR. With the help of our charity collaborators – Epilepsy Action, SUDEP Action, Young Epilepsy, Epilepsy Society and the International League Against Epilepsy (ILEA) British Branch we reached out to every corner of the epilepsy community – people living with the condition, families, friends, carers, those bereaved by epilepsy, healthcare professionals and organisations representing the interests of people affected by epilepsy and associated conditions.

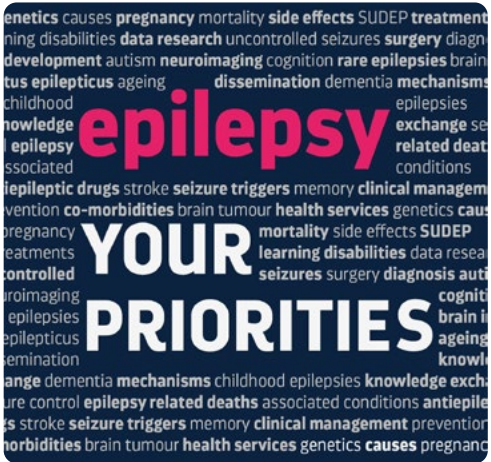
We received **2,014 responses** from across the UK. These responses have resulted in over **5,418 priorities** for research. Collectively, they present a wide range of themes, from sudden unexpected death in epilepsy (SUDEP) to surgery, seizure triggers to support, side effects to stigma. Almost half (46%) of responses were from people with epilepsy, closely followed by family members of those who have or had epilepsy at 32%.



“The unified voice of the epilepsy community will be an essential tool in influencing government, and institutional and strategic funders to invest more in this chronically underfunded area of research and will support our own plans for sustainability. The rigorous approach we have taken will provide us with the evidence we need to share the future of research.” **Dr Rhys Thomas**

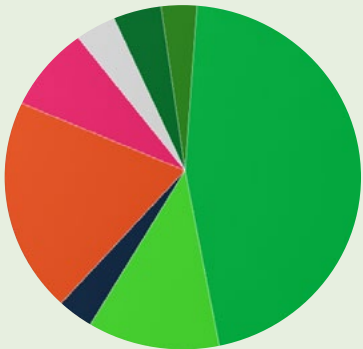
With the support of the UK Epilepsy PSP Steering Group, our research team has reviewed and categorised the priorities into a longlist of in-scope and currently unanswered priorities. This longlist has then been interpreted into summary questions and shared with the epilepsy community for shortlisting.

The shortlist will be discussed at the UK Epilepsy Priority Setting Workshop, where representatives from across the epilepsy community will determine the Top 10 priorities for research into epilepsy. The Top 10 priorities will be published in the autumn and will unite epilepsy and associated condition charities, driving collaborations. Once published, it will provide an evidence base to ensure Epilepsy Research UK and other funding bodies are aligned with the priorities of the epilepsy community.

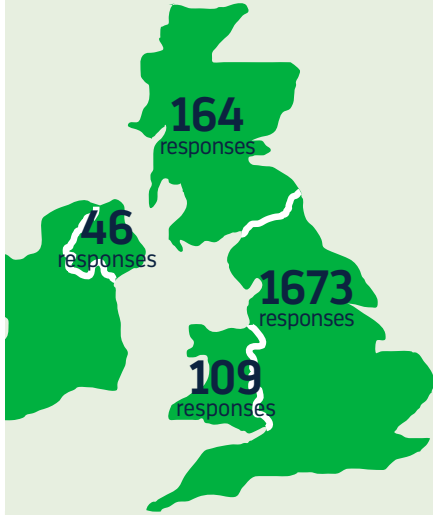


WHICH OF THE FOLLOWING BEST DESCRIBES YOU?

- Person with epilepsy
- Healthcare professional
- From an organisation representing the interest of people affected by epilepsy
- Parent of someone with epilepsy
- Family member or friend of someone with epilepsy
- Caregiver or former caregiver of someone with epilepsy
- Bereaved family member or friend of someone who had epilepsy
- Other

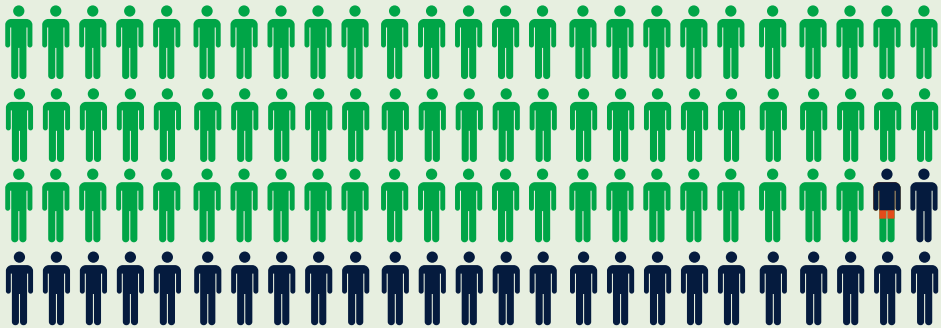


WHERE DO YOU LIVE?

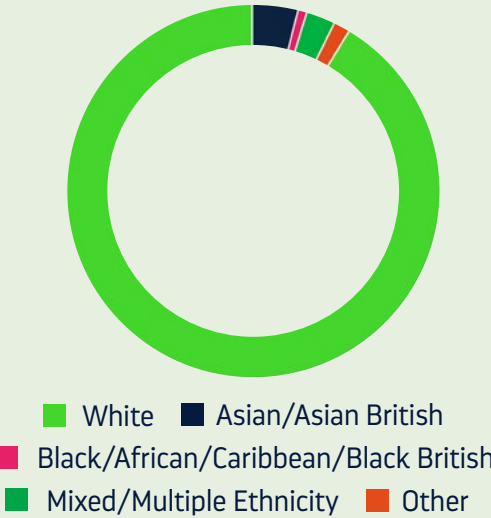


GENDER

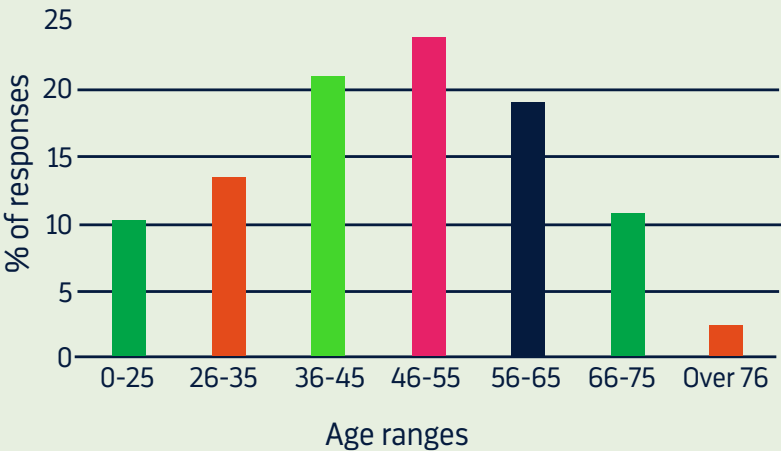
- 72.7% female
- 26.6% male
- 0.66% prefer to self-describe



ETHNICITY



AGE



TARGET TWO: CONNECTING RESEARCHERS WITH PEOPLE AFFECTED BY EPILEPSY

We have built the largest-ever community of 'research-interested' people affected by epilepsy. The over 400-strong Shape Network are now actively involved in our daily activities; from being UK Epilepsy PSP steering group members to involvement in our own grant round 'Application Clinics' and sharing their knowledge and experiences through our webinars, blogs and case studies. We also continued to promote the evidence of chronic underfunding in epilepsy research as part of the 'ALife Interrupted' report and campaign.



SHAPE
EPILEPSY
RESEARCH
NETWORK

INVOLVING THE EXPERTS BY EXPERIENCE

Established in October 2020, the Epilepsy Research UK Shape Network has recruited over 400 people affected by epilepsy – the largest ever network of ‘research interested’ people dedicated to influencing and shaping the future of epilepsy research.

People living with epilepsy have valuable experience and insights that can help all stages of the research process, from planning and study design to communicating results. They can influence the direction of research and, crucially, ensure it is focused on what will make the biggest difference to them and their families.

We have developed an infrastructure and environment for those affected to help research flourish. The Shape Network is an important part of Epilepsy Research UK’s strategy to support capacity building activities for researchers and is placing people affected by epilepsy at the centre of our work as a charity. Through this network we are ensuring research is focused on the most important outcomes identified by people affected by epilepsy and will provide the evidence needed to secure greater research funding.

FOSTERING AND STRENGTHENING COLLABORATIONS

Patient and public involvement in research has become increasingly important and there is now a recognition that it leads to higher quality studies. But it’s not without its challenges. For some researchers, PPI presents a new way of working. While they undoubtedly see the benefits, in practice some researchers may find it difficult to identify how they should select and involve patients. People affected by epilepsy may find the scientific jargon inaccessible or struggle to understand what the research is trying to achieve. They have also reported that the PPI process can feel like a box ticking exercise. We’ve developed our Shape Network to overcome these barriers and to foster and strengthen the collaboration between the people affected by epilepsy and researchers.



FOR PEOPLE LIVING WITH EPILEPSY

We are providing an ongoing programme of education and preparation workshops so network members understand the research process and their role in supporting high-quality studies.



FOR RESEARCHERS

We are facilitating and guiding the engagement with people affected by epilepsy, ensuring the process is planned appropriately and that study information is accessible.

FROM RECRUITMENT TO RESEARCHERS

Our Shape Network is ensuring that the voices and priorities of people affected by epilepsy are considered in the projects we are funding. We have successfully piloted the involvement of network members in our research funding processes and connected researchers with network members to improve existing studies.



THE SHAPE NETWORK IN ACTION

This year we launched the Shape Network Application Clinics as part of our annual grant application assessment process. The clinics gave researchers the opportunity to meet members of the network to discuss their proposed research. By involving people affected by epilepsy in the development of a proposal, we are supporting researchers to produce stronger applications.



WHAT IS AN APPLICATION CLINIC?

Our application clinics bring together researchers and people affected by epilepsy to encourage and enable discussion and debate about a potential grant application.

HOW DO THEY WORK?

Researchers attend a virtual meeting with two members of the Shape Network that is facilitated by Epilepsy Research UK. During the clinics, discussion topics include how the research will benefit people affected by epilepsy and how best to involve people with lived experience. Network members also advise the researcher on ways to make the complex scientific language more accessible, and how best to communicate the potential impact of the research.

“ I really enjoyed being involved in the application clinics as part of the Shape Network, and found the research applications so interesting. Wonderful to meet so many researchers and learn about the exciting research going on in labs and hospitals around the UK. Application Clinic Volunteer ”

HOW ARE THEY MAKING A DIFFERENCE?

For researchers, understanding the needs of people affected by epilepsy, working through the practicalities of research involvement, and demonstrating the potential impact of a project is invaluable. For people affected by epilepsy, knowing they have influenced the potential success of life-changing research is hugely rewarding. For Epilepsy Research UK, we know this is another vital step in ensuring the research we fund has been rigorously assessed by experts by experience.



“ During this year’s grant round, Shape Network members contributed valuable expertise gained from their lived experience, complementing the research expertise of the Scientific Advisory Committee (SAC). This involvement at the key stages in the decision-making pathway will accelerate further progress by ensuring people affected have supported Epilepsy Research UK to fund the best and most impactful projects. ” Professor Mike Cousin, Epilepsy Research UK SAC Chair

TARGET THREE: STRONGER TOGETHER - BUILDING PARTNERSHIPS & COLLABORATIONS

This year we were proud to co-fund a clinical Fellowship with charity partners, The Association of British Neurologists and Stroke Association. We began fostering relationships with industry and pharma resulting in a strategic partnership with Angelini Pharma to commission data-driven research to understand and predict important clinical outcomes in refractory epilepsy. And our partnership working extended beyond co-funding to fundraising with the launch of the Brainathon virtual event series in association with the fantastic teams at Brain Tumour Research and Brain Research.





ARE WE AT A TIPPING POINT?

“

We are now at a tipping point. We need to leverage the published evidence to affect the change so urgently needed to drive greater investment in epilepsy research. If we don't act now the opportunity cost would be enormous. ”

Professor Helen Cross OBE
#Every1EndingEpilepsy programme director

WE ARE APPROACHING TIPPING POINT

Chronic underinvestment in epilepsy research has meant effective treatments for everyone living with the condition are still decades away. But together we can change this. Right now, there are policy shifts relating to long-term health conditions, brain health and multi-morbidities that we must leverage. We are at a tipping point

NICE Guidelines published April 2022

NICE published its new guidance and advice on the diagnosis and management of epilepsy. The guidelines include research recommendations, which provide an insight into the key areas of epilepsy where more research is needed. These include antibody testing, investigating the role of immunomodulation strategies, anti-seizure therapies for complex epilepsy syndromes, risk reduction tools for all causes of epilepsy-related death and vagus nerve stimulation. Other recommendations for future research included psychological treatments, the monitoring of anti-seizure medications in women and girls, and the role of digital health technologies.



The World Health Organisation (WHO) Intersectoral Global Action Plan (IGAP) on Epilepsy

Approved in May, the IGAP has the potential to bring about significant change in policy and practise around the world. It covers a 10-year period from 2022-31 and will build on existing global resolutions, commitments and reports which have previously highlighted challenges presented by epilepsy. As part of the strategic initiatives outlined in the report, there are a number of recommendations for research initiatives to foster research and innovation and strengthen information systems.

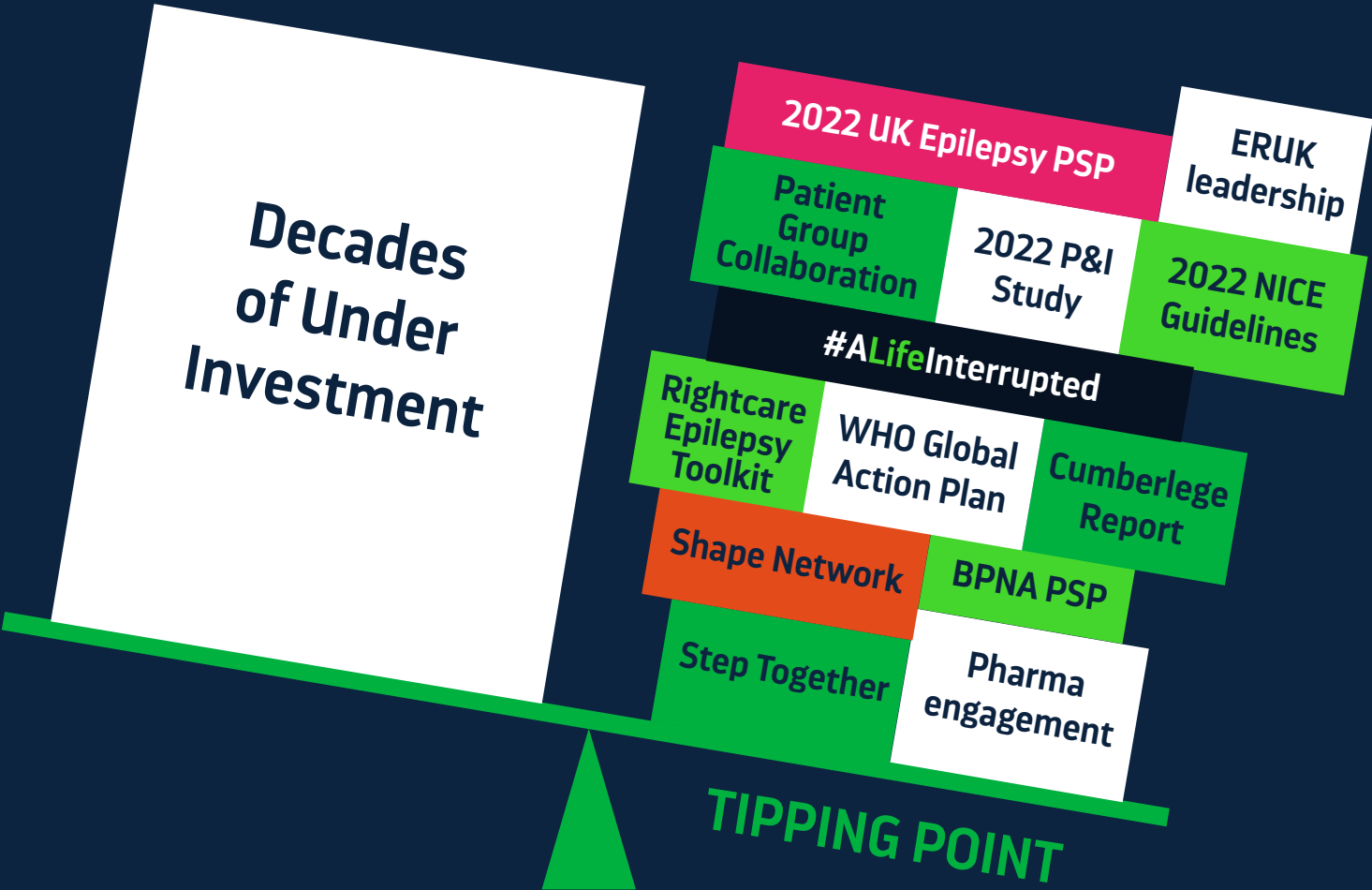


Governments around the world are now tasked with responding to the recommendations. These IGAP recommendations, together with new NICE Guidelines and the results of the UK Epilepsy Priority Setting Partnership, will shape future research for the next generation

HARNESSING THE MOMENT

Our calls for increased research investment, to foster national and international collaborations and improve Research infrastructure have now been greatly boosted by the WHO IGAP recommendations.

But this is just the beginning. We must now harness the moment and capitalise on these developments to finally end the neglect and chronic underfunding epilepsy has so far experienced. Our preparation in 2021/22 for the IGAP approval means we are both ready and positioned to stimulate and assist the government with their responsibility to respond to the recommendations. Our work in 2022/23 will be focused on doing exactly this. We will show them how to do it. We will provide the roadmap for delivery.



#Every1EndingEpilepsy

Demanding £100 for every 1 in 100

to radically advance research into epilepsy
through investment, collaboration
and action.

#Every1EndingEpilepsy Programme

As the only UK charity solely dedicated to driving and enabling research into epilepsy, Epilepsy Research UK is preparing to leverage the momentum of the IGAP and other recent initiatives to drive research forward. By bringing together those working in epilepsy and those affected by epilepsy to develop a programme of work, the aim is to radically advance research through investment, collaboration and action.

As a first step, a national epilepsy research collaborative, led by three of the UK's leading clinicians and researchers – Professor Tony Marson (The Walton Centre, University of Liverpool), Professor Helen Cross OBE (UCL Great Ormond Street Institute of Child Health) and Professor Mark Richardson (King's College London) will identify and prioritise a programme to drive research breakthroughs in diagnostics, treatments and prevention of epilepsy.



“By uniting funders, people affected by epilepsy and expert researchers we will be able to catapult innovations in research that have the potential to be delivered in a generation.”

Professor Mark Richardson, #Every1EndingEpilepsy programme director

The #Every1EndingEpilepsy programme will provide a road map to the UK government to enable them to implement the recommendations from the IGAP and will be supported by a strategic communications campaign led by people affected by epilepsy. The campaign will seek a commitment from the government to a research investment of £100 for each of the estimated 600,000 people living with epilepsy in the UK. That's £100 for every 1 in 100 – a £60 million accelerator fund.

“Whilst we are doing our best to understand the biology underpinning the epilepsies and develop new treatments, there's so much more we can do to improve the quality of care people with epilepsy receive and to diminish the health inequalities that are associated with epilepsy. We desperately need the community to come together so we can deliver the much needed research to improve the lives of people with epilepsy.”

Professor Tony Marson, #Every1EndingEpilepsy programme director



#Every1EndingEpilepsy will raise public awareness of the impact of epilepsy and demonstrate how, by working collaboratively, we can bring about a radical change within a generation



“I lost my sister to epilepsy. The grief is unimaginable. We want to prevent this from happening to other families like ours. But there are still 21 epilepsy-related deaths every week. That's why we're demanding the government invest £100 for every 1 in 100 people living with epilepsy.”

Joyce Meads, campaigner and supporter for Epilepsy Research UK

THANK YOU

Once again, everything we've been able to do this year is because of our amazing supporters. **Thank you.** Whether from regular monthly donations, gifts in Wills or fundraising challenges, please know that your efforts have a direct impact on researchers' ability to stop the devastation caused by epilepsy.



WE STILL NEED YOU

By continuing to support Epilepsy Research UK in the year ahead, you can help us to continue our vital work and harness the huge exciting opportunities to fast track epilepsy research. **The scales have tipped. Now let's push them all the way.**

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

YEAR ENDING 31ST MARCH 2022

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 2022 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)
 The Rt Hon David Cameron
 Professor Michael Cousin BSc PhD
 Dr Anne Coxon DPsych
 Ms Mary Gavigan BBS MA FCA
 Dr John Hirst CBE BA FCA MCT CCBIM DSc
 Mr Simon Lanyon (retired 6th August 2021)
 Professor Nicholas Lench BSc, PhD, FRCPPath (appointed 15th September 2021)
 Mr Thomas McLaughlan BA (Hons) (resigned 15 June 2022)
 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

President

Professor Helen Cross MB ChB PhD FRCP(UK) FRCPCH

Chief Executive

Ms Maxine Smeaton MSc PGDip MInstF

Independent auditors

MG Audit Services Limited, Chartered Accountants and Statutory Auditors
 166 College Road, Harrow, Middlesex, HA1 1BH

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
 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.

Continued impacts of the pandemic

Income

Like the majority of charities in our sector, we continue to experience a drop in voluntary income (12.5% compared to the previous three years' income) due to the postponement of mass participation events and community fundraising activities. Whilst we have continued to market a range of virtual products and introduced new products such as the 'Brainathlon', we are acutely aware that interest has waned for such events. We have invested significant effort in segmenting our donor database to ensure we are developing a targeted approach. We continue to engage and steward our supporters where possible, and this year have tested several different themes and approaches to fundraising campaigns. Whilst growth has been limited, we are pleased to have maintained a steady income in such challenging circumstances.

Research

We made several adjustments to our research activities during 2021/22

- Due to the continued uncertainty regarding international travel, plans to reschedule the International Expert Workshop were put on hold. Instead, we announced plans to launch a new series of seminars, hosted and chaired by Epilepsy Research UK Fellows - the 'Navigator Series'.
- We took the decision not to fund the Explore Pilot studies and to only fund ERUK Emerging Leader Fellowship Awards and Endeavour Project Grants in the grant round in 2021/22.

Key achievements

In 2021 we set out our plans to deliver our **Going Further** Strategy. The key areas of focus for 2021/22 were:

Strengthening and expanding the landscape of epilepsy research – Gathering the evidence urgently needed to drive strategic investment

We have led, funded and collaborated to produce a once in a generation national survey, the UK Epilepsy

Priority Setting Partnership, commissioned and released an epilepsy and autism dossier in partnership with Autistica and Young Epilepsy and continued to promote the evidence of chronic underfunding as part of the 'ALifeInterrupted' report and campaign.

Listening and actively involving people affected by epilepsy in priority-setting - Developing a patient-centric mission, embracing complexity, driving collaborations

We have attracted and secured over 400 'research-interested' people affected by epilepsy who are now active participants in our daily activities, from being steering group members of the UK Epilepsy PSP, to involvement in our own grant round through 'Application Clinics' to contribute to our own webinar/blogs and #ALI case studies

Capacity building the infrastructure that supports knowledge and information - Bringing experts together to accelerate breakthroughs, developing a credible capability in areas such as data aggregation

We have begun work on the development of a strategic initiative 'a Moonshot' ambition. We have formed a steering group and held the first workshop to help define the desire and purpose.

Nurturing and fast-tracking the best and brightest minds in epilepsy - Providing opportunities for the best clinicians and scientists to embark on a lifelong commitment to researching epilepsy.

We have launched the 'Navigator Series' a new series of seminars, hosted and chaired by Epilepsy Research UK Fellows -and co-funded a Fellowship with the Association of British Neurologists (ABN) and Stroke Association.

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 2022 of £2,638,488. 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

As part of our plans to develop the building blocks to a strategic plan, we have been implementing a programme to gather the evidence required to drive a strategy for further investment into epilepsy research. The following key activities began in 2021/22:

Shape Network Roll Out

The Epilepsy Research UK Shape Network has recruited over 400 people affected by epilepsy – the largest ever network of 'research interested' people dedicated to influencing and shaping the future of epilepsy research. People living with epilepsy have valuable experience and insights that can help all stages of the research process, from planning and study design to communicating results. They can influence the direction of research and, crucially, ensure it is focused on what will make the biggest difference to them and their families.

We have developed an infrastructure and environment for those affected to help research flourish underpinned by five strategic priorities developed by the Shape Network steering group to ensure a successful outcome for both researchers affected by epilepsy:

- Creating a powerful community of research-interested people affected by epilepsy
- Connecting researchers and people affected by epilepsy
- Involving people affected by epilepsy in research
- Advocating for greater investment into epilepsy
- Collaborating with rare epilepsy and associated condition organisations

The network has already contributed to Epilepsy Research UK’s own 2021/22 grant round, through the development of ‘Application Clinics’. The network has also been active participants in the UK Epilepsy Priority Setting Partnership. We have been invited to collaborate on a number of grant applications as the co-production experts. Further information about the Shape Network’s activities were published in the Spring 2022 edition of the Focus newsletter.

UK Epilepsy Priority Setting Partnership

In November 2021, Epilepsy Research UK launched the UK Epilepsy Priority Setting Partnership (PSP) in conjunction with the James Lind Alliance and NIHR. This once in a generation national survey has gathered the views of the entire UK epilepsy community: people living with the condition, families, friends, carers, those bereaved by epilepsy, healthcare professionals and organisations representing the interests of people affected by epilepsy and associated conditions.

To ensure the UK Epilepsy PSP was truly representative, we reached out to all charities connected to epilepsy. With the help of our charity collaborators – Epilepsy Action, SUDEP Action, Young Epilepsy, Epilepsy Society and the International League Against Epilepsy (ILAE) British Branch – and our national and regional partner organisations, our collective networks have reached every corner of the UK, and we have achieved a true representation of the diversity found in the UK and its epilepsy community.

We received 2014 responses from the length and breadth of the UK, each contributing one, two or three priorities, these responses have resulted in over 5,418 priorities. Collectively, they present a wide range of themes, from sudden unexpected death in epilepsy (SUDEP) to surgery, seizure triggers to support, side effects to stigma. The inclusivity, scale and diversity of responses to the UK Epilepsy PSP survey reflects not only the enormity of the epilepsy community but your desire to be heard, treated equally and to drive change. Contributing 46% of all responses, people with epilepsy were the loudest voice in the survey, while the parents, family and friends of those who have or had epilepsy collectively represent 32%.

Through this programme of work, we are shaping the future of research into epilepsy. The priorities we publish will unite epilepsy and associated condition charities, driving collaborations between them. It will ensure that the research championed by Epilepsy Research UK and other funding bodies is rooted in the priorities of the entire epilepsy community. It will also help us to influence government and institutional funders to give epilepsy an equitable share of research investment, so innovations in the diagnosis and treatment of epilepsy will no longer lag behind other less prevalent conditions.

Publication of UK Epilepsy Priority Setting Partnership Top 10 Priorities

The survey submissions are currently under review and being categorised into a longlist of in-scope and unanswered priorities. Once identified, this longlist will be interpreted into summary questions and shared with the epilepsy research community. The shortlist of research questions chosen by the epilepsy community

will be discussed at a UK Epilepsy Priority Setting Workshop, where representatives from across the epilepsy community will be present to discuss the shortlist and determine the Top 10 priorities for research into epilepsy.

The priorities we publish will unite epilepsy and associated condition charities, driving collaborations between them. It will ensure that the research championed by Epilepsy Research UK and other funding bodies is rooted in the priorities of the entire epilepsy community. It will also help us to influence government and institutional funders to give epilepsy an equitable share of research investment, so innovations in the diagnosis and treatment of epilepsy will no longer lag behind other less prevalent conditions.

Strategy Development

Developing an Epilepsy Research Moonshot Ambition

The new generation of Medical Research Charities are increasingly ambitious in their vision to drive a better future for the conditions they support. Several charities have acknowledged the lack of progress in their disease areas and have defined “Moonshot” ambitions to deliver transformational patient benefit. By doing so they have not only multiplied the fundraising ask to unprecedented levels but have laid down a compelling case for support to donors and policymakers.

For epilepsy, the inequalities in research funding have meant progress has been slow. A strategic, systematic and long-term approach is required to make a tangible difference. In 2022 we want to develop a UK Epilepsy Research Moonshot that will accurately define priority actions for improving epilepsy research capacity which, if adopted, will reduce the individual, social and economic impact of epilepsy and be life-changing for people living with the condition.

National Research Collaboration - #Every1EndingEpilepsy

Over the past few years, Epilepsy Research UK has established a strong position in the epilepsy community by developing a brand based on trust and authenticity, growing partnership and collaboration activities and leading strategic programmes of work that are both patient-centric and evidence-based. We have developed our role as leaders through the UK Epilepsy Priority Setting Partnership and are respected for our integrity when bringing clinicians, researchers, people affected by epilepsy and our charity partners together. We are now in a strong position to lead and drive a strategy to capacity build the epilepsy research environment.

There are currently policy shifts relating to long-term health conditions, brain health and multi-morbidities that could be leveraged to secure major investment. We are at a tipping point. By working collaboratively to generate ideas and shape the research environment, we can advance research to end epilepsy.

- In March 2022, **NICE** published **revised guidelines** detailing recommendations where more research is needed.
- Epilepsy Research UK has funded and led a **James Lind Alliance UK Priority Setting Partnership**.
- **The World Health Organization’s Intersectoral Global Action Plan on epilepsy, the WHO IGAP, has been published** and requires governments worldwide to respond to the recommendations, potentially bringing about real change in policy and practice.

Epilepsy Research UK is therefore leading a programme to bring everyone together to respond to the key recommendations and stimulate and assist the government to implement the responsibility to key recommendations to foster research and innovation. The **#Every1EndingEpilepsy** programme will develop a road map for delivery that will focus on prevention, closing the treatment gaps, reducing epilepsy deaths and improving lives. **We are at a tipping point. The time is now.**

Research grants in 2022

This year we awarded nine research grants totalling over £1.5 million, with each project looking at a particular aspect of the cause, prevention, or treatment of epilepsy. This funding includes four Emerging Leader Fellowship Awards to support four early career researchers to become future leaders in epilepsy research, across areas such as public health, genetic epilepsies, SUDEP, and cardiovascular health and epilepsy

Summary of research grants awarded

PRINCIPAL INVESTIGATOR, INSTITUTION	TITLE	AMOUNT
Dr Kathryn Bush Newcastle University	Understanding epilepsy inequalities in the UK	£249,993
Dr Amol Bhandare University of Warwick	Investigating the role of microglia in drug-resistant seizures, sudden death and memory function in epilepsy	£249,570
Dr Faye McLeod Newcastle University	Exploring the mechanisms behind early onset genetic epilepsies using human brain tissue	£250,000
Dr Jospehine Mayer University of Liverpool	Joint funding with Association of British Neurologist & Stroke Association: Exploring the link between seizures and cardiovascular health in the aging population	£88,470
Dr Karen Smillie University of Edinburgh	Causal relationship between activity-induced synapse sprouting and epileptogenesis	£149,994
Dr Rob Wykes University College London	The contribution of spreading depression (SD) to postictal generalised EEG suppression (PGES): Onset and recovery	£139,716
Dr Sukhvir Wright Aston University	Can we extinguish the seizures in FIRES?	£145,591
Dr Jonathan Lippiat University of Leeds	Evaluating the efficacy of potassium channel inhibitors in KCNT1-associated epileptic disorders	£141,236
Dr Sophie Adler University College London	Multi-centre Epilepsy Lesion Detection Project: a collaborative cohort for the analysis of focal epilepsies	£148,279
Dr Colin Reilly UCL, Great Ormond Street Institute of Child Health	Joint funding with Autistica – Autism and epilepsy : laying out the evidence	£10,000
Total grants awarded		£1,572,849

In addition, we are currently funding 42 other projects, approved in prior years, at institutes around the country, examples of which include 13 PhD studentships across two Doctoral Training Centres in Newcastle and Edinburgh, as well as studies investigating ground-breaking gene therapy techniques to prevent seizures and novel neuroimaging studies to make bedside brain imaging a reality.

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 **£5.3 million** on research grants and these have **leveraged over £31.4 million** in follow-on funding from other sources. Therefore, every pound invested by Epilepsy Research UK has **generated a further £5.91 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. Over **300** journal publications have resulted from ERUK grants during the 2009 – 2021 period, **38** 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 (ie the number of times the publications have been referred to by other researchers in their own work). In this case our publications have been cited over 3,500 times.

Fundraising performance in 2021/22

The overall incoming resources from fundraising and trading activities during 2021/22 were £1,244,468 an increase in income of 76% compared to the previous year due. This was largely boosted by a one-off £485k grant for existing early career researchers from BEIS and DHSC in recognition of the losses experienced by medical research as a result of Covid-19. Legacy income in the year was £1, 522,836. 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.

Our fundraising approach

Last year, 93% of our funding primarily came from our community of supporters despite the continued restrictions imposed by the global pandemic. We greatly appreciate and recognise the importance and value of the relationship with our supporters. We ensure our supporters are informed and inspired by the way the organisation both raises and spends its funds. We are mindful of the impact inflation and the cost-of-living crisis will have on our supporters and will ensure that we are clear in demonstrating the impact of our work and that our fundraising targets and campaigns are appropriate.

Many of our supporters take part in events to raise

money through sponsorship. Whilst we are seeing a gradual return to in-person events, we continue to offer a range of virtual events to take part in. Where events take place in person, we have clear written contracts with suppliers and there is full transparency of the costs involved.

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 Regulations (GDPR)

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

As we moved to a hybrid working model in 2021 we developed a plan to ensure we remained compliant. We use VPNs to safeguard access to our donor database and operate a no-paper policy so that all communications are held digitally on our secure environment.

Financial review

In 2021/22 our overall incoming resources were £2,987,008 and the costs of raising funds were £174,650 leaving £2,812,358 available for charitable activities. This was an increase in net income of

£1,745,014 compared to the previous year. The total spent on charitable activities was £2,092,088.

This year we were fortunate in receiving a one-off grant of £485,319 from the government to compensate for delays to research for early career researchers. We also had exceptional levels of legacy income. The legacy income budget for the year was for a more modest level of £470,000. The current level of legacy income has 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 2022 of £1,572,849 a similar level to 2021. It is envisaged the impact of the Covid pandemic and cost of living crisis will continue to influence income over the next couple of years and the designated research fund at 31 March 2022 will be utilised to try to maintain research grants at a similar level for the foreseeable future.

Bank balances of £3,026,035 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. Income from investments performed well until the latter part of the year when hostilities overseas created a sudden drop in value. There was an unrealised gain on investment value in the year of £20,557.

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 re-appointment. 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 Bayess Business School this 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 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 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 Group’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 ongoing Coronavirus and cost of living crisis.
- 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 2022 are £1,738,488 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 trustee 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

14th September 2022

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 2022 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 2022 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 Charities Act 2011

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 auditors 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 16, 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

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 the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

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 purpose of expressing an opinion on the effectiveness of the charity'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 charity'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 charity 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.

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.

Use of our report

This report is made solely to the charity Trustees, as a body, in accordance with section 144 of the Charities Act 2011 and regulations made under section 154 of that Act. Our work has been undertaken so that we might state to the Trustees those matters we are required to state to Trustees in an auditors' 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 and its Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Mr Gavin Fernandes FCA (Senior Statutory Auditor)
MG Audit Services Limited, Chartered Accountants & Statutory Auditors

166 College Road, Harrow, Middlesex, HA1 1BH

Statement of Financial Activities
(including the Income & Expenditure Account)
for the year ended 31st March 2022

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £	Total Funds 2021 £
Income from:					
Donations and legacies	2	2,148,381	593,331	2,741,712	1,112,408
Charitable activities research grants not required	6	133,585	-	133,585	32,635
Other trading activities	3	25,592	-	25,592	16,495
Investments	4	86,119	-	86,119	64,741
Total Income		2,393,677	593,331	2,987,008	1,226,279
Expenditure on:					
Raising Funds	5	174,650	-	174,650	158,935
Charitable Activities:					
Research grants committed	6	1,572,849	-	1,572,849	1,320,966
Other research activities	7	471,121	48,118	519,239	518,748
Total Charitable Activities		2,043,970	48,118	2,092,088	1,839,714
Total Expenditure	10	2,218,620	48,118	2,266,738	1,998,649
Net unrealised Gains / (Losses) on investments		20,557	-	20,557	253,089
Net Income/(Expenditure) for the year		195,614	545,213	740,827	(519,281)
Transfers between funds	16	499,331	(499,331)	-	-
Net Movement in Funds for the year		694,945	45,882	740,827	(519,281)
Reconciliation of Funds:					
Total funds brought forward on 1 April 2021		1,943,543	27,360	1,970,903	2,490,184
Total funds carried forward at 31 March 2022	15, 16	2,638,488	73,242	2,711,730	1,970,903

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 19 to 32 form part of these financial statements.

Balance Sheet at 31st March 2022

	Note	2022 £	2021 £
Fixed Assets - Investments	11	<u>3,897,165</u>	<u>2,311,606</u>
		3,897,165	2,311,606
Current Assets			
Debtors	12	740,075	608,632
Cash at bank and in hand	13	<u>3,026,035</u>	<u>3,399,537</u>
		3,766,110	4,008,169
Creditors: Amounts falling due within one year	14	(2,007,029)	(1,956,691)
Net Current Assets		<u>1,759,081</u>	<u>2,051,478</u>
Total Assets less Current Liabilities		5,656,246	4,363,084
Creditors: Amounts falling due after more than one year	14	<u>(2,944,516)</u>	<u>(2,392,181)</u>
Total Net Assets		<u>2,711,730</u>	<u>1,970,903</u>
The Funds of the Charity			
Unrestricted Funds			
Designated Funds	15	1,738,488	1,042,684
General Fund	15	<u>900,000</u>	<u>900,859</u>
		2,638,488	1,943,543
Restricted Funds	16	<u>73,242</u>	<u>27,360</u>
Total Charity Funds		<u>2,711,730</u>	<u>1,970,903</u>

The financial statements were approved by the Board of Trustees on the 14th September 2022 and signed on its behalf by:

Prof Matthew Walker
Chair

Judith Spencer-Gregson FCA
Treasurer

The notes on pages 19 to 32 form part of these financial statements.

Statement of Cash Flows for the year ended 31st March 2022

	Note	2022 £	2021 £
Cash Inflow from Operating Activities	19	<u>1,105,381</u>	<u>414,578</u>
Cash Flows from Investing Activities			
Sale of investments	28	472,588	
Net purchase of investments	(1,500,000)	(469,964)	
Income reinvested	(65,030)	(44,245)	
Dividends and interest received	86,119	64,077	
Net Cash (Outflow)/Inflow from Investing Activities		<u>(1,478,883)</u>	<u>22,456</u>
(Decrease)/Increase in Cash and Cash Equivalents in the Year		<u>(373,502)</u>	<u>437,034</u>
Cash and Cash Equivalents at the Beginning of the Year		<u>3,399,537</u>	<u>2,962,503</u>
Cash and Cash Equivalents at the End of the Year		<u>3,026,035</u>	<u>3,399,537</u>

Notes
forming part of the financial statements for
the year ending 31st March 2022

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 2022 £	Total 2021 £
Charitable trusts	44,483	94,600	139,083	89,324
In memoriam donations	88,452	-	88,452	73,289
Other donations	267,448	498,731	766,179	373,627
Fundraising events	225,162	-	225,162	152,431
Legacies	1,522,836	-	1,522,836	423,737
	<u>2,148,381</u>	<u>593,331</u>	<u>2,741,712</u>	<u>1,112,408</u>

Donations and Legacies 2021

	Unrestricted Funds £	Restricted Funds £	Total 2021 £
Charitable trusts	30,324	59,000	89,324
In memoriam donations	73,289	-	73,289
Other donations	350,627	23,000	373,627
Fundraising events	152,431	-	152,431
Legacies	413,737	10,000	423,737
	<u>1,020,408</u>	<u>92,000</u>	<u>1,112,408</u>

Income from fundraising events arises from events organised by the charity and its supporters. Online advertising to the value of £78,821 (2021 £72,630) 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 2022 £	Unrestricted Total 2021 £
Sale of Christmas cards	22,592	-	22,592	16,495
Fees charged	3,000	-	3,000	-
	<u>25,592</u>	<u>-</u>	<u>25,592</u>	<u>16,495</u>

4 Investment Income

	Unrestricted Funds £	Restricted Funds £	Total 2022 £	Unrestricted Total 2021 £
Realised gain on investments	-	-	-	664
Dividend & investment income	82,790	-	82,790	58,536
Interest on deposits	3,329	-	3,329	5,541
	<u>86,119</u>	<u>-</u>	<u>86,119</u>	<u>64,741</u>

5 Costs of generating funds

	Note	Unrestricted Funds £	Restricted Funds £	Total 2022 £	Unrestricted Total 2021 £
Direct fundraising		63,269	-	63,269	53,891
Staff costs		89,215	-	89,215	82,412
Other overhead expenses	8	15,537	-	15,537	16,884
Governance costs	8	6,629	-	6,629	5,748
		<u>174,650</u>	<u>-</u>	<u>174,650</u>	<u>158,935</u>

6 Research Grants Committed

	2022 £	2021 £
Committed as at 31 March 2021	4,298,279	3,582,237
Authorised during year (see Trustees’ report)	1,572,849	1,320,966
No longer required	(133,585)	(32,635)
Paid in year	(824,498)	(572,289)
Committed as at 31 March 2022	4,913,045	4,298,279

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 Annual Report on pages 8-13. Details of all grants awarded are available on the website: www.epilepsyresearch.uk/ Research grants no longer required relates to projects that were completed without the original grant being spent.

7 Other Research Activities

	Note	Unrestricted Funds £	Restricted Funds £	Total 2022 £	Total 2021 £
Staff costs		268,963	35,441	304,404	302,512
Scientific workshop		-	-	-	-
Research meetings, events & activities		12,571	-	12,571	5,020
Research awards & prizes		236	500	736	600
Research dissemination & communication		118,034	5,535	123,569	124,904
Overhead expenses	8	48,704	6,642	55,346	64,611
Governance costs	8	22,613	-	22,613	21,101
		471,121	48,118	519,239	518,748

Other Research Activities 2021

	Unrestricted Funds £	Restricted Funds £	Total 2021 £
Staff costs	302,512	-	302,512
Scientific workshop	-	-	-
Research meetings, events & activities	5,020	-	5,020
Research awards & prizes	-	600	600
Research dissemination & communication	124,904	-	124,904
Overhead expenses	64,611	-	64,611
Governance costs	21,101	-	21,101
	518,148	600	518,748

8 Support and Governance costs

	Support Costs £	Governance Costs £	Total 2022 £	Total 2021 £
Staff costs	-	10,729	10,729	9,333
Other staff costs	14,914	-	14,914	13,400
Office rent & facilities	20,865	-	20,865	31,758
Office running costs	12,245	-	12,245	20,072
IT & bank charges	22,859	-	22,859	16,265
Investment fees	-	18,367	18,367	18,924
Audit	-	5,562	5,562	4,600
Trustee meetings & expenses	-	2,912	2,912	-
Legal & professional fees	-	2,400	2,400	3,325
	70,883	39,970	110,853	117,677

Basis of Allocation

Allocated to fundraising costs	15,537	11,994	27,531	24.84%
Allocated to charitable activities	55,346	27,976	83,322	75.16%
	70,883	39,970	110,853	100.00%

Support and Governance costs 2021

	Support Costs £	Governance Costs £	Total 2021 £
Staff costs	-	9,333	9,333
Other Staff Costs	13,400	-	13,400
Office rent and facilities	31,758	-	31,758
Office running costs	20,072	-	20,072
IT and bank charges	16,265	-	16,265
Investment fees	-	18,924	18,924
Audit	-	4,600	4,600
Trustee meetings & expenses	-	-	-
Legal & professional fees	-	3,325	3,325
	81,495	36,182	117,677

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	100.00%

9 Net incoming resources are after charging the following:

	2022 £	2021 £
Auditors’ remuneration	5,562	4,600
Payroll fees	846	1,200

10 Staff Costs

	2022 £	2021 £
Salaries	346,535	338,769
Social security costs	33,743	32,867
Pension costs	13,341	13,287
	<u>393,619</u>	<u>384,923</u>

One employee earned between £70,000 and £80,000 (2021: one).

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

	2022	2021
Charitable activities	1.73	6.01
Fundraising	5.99	1.79
Governance	0.13	0.10
	<u>7.85</u>	<u>7.90</u>

The Trustees do not receive any remuneration for their duties and during the year received expenses of £683 for travelling to meetings (2021: £0). No trustee or persons with family or business connections with Trustees has received remuneration directly or indirectly from the charity. The charity includes Trustee’s Liability Insurance in its combined insurance policy.

11 Investments

	2022 £	2021 £
Market value 1 April 2021	2,311,606	2,016,232
Acquisitions	1,500,000	469,964
Sales	(28)	(472,588)
Investment charges	(18,367)	(18,924)
Income reinvested	83,397	63,169
	<u>3,876,608</u>	<u>2,057,853</u>
Net gain/(loss) realised	-	664
Net gain/(loss) unrealised	20,557	253,089
Market value 31 March 2022	<u>3,897,165</u>	<u>2,311,606</u>

Analysis of investments

Quoted Charity Common Investment funds	3,380,546	2,294,209
Medium and long term	516,619	17,397
	<u>3,897,165</u>	<u>2,311,606</u>

12 Debtors

	2022 £	2021 £
Gift Aid recoverable	6,633	20,831
Prepayments & accrued income	733,442	587,801
	<u>740,075</u>	<u>608,632</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 2022 £
Balance as at 31 March 2021	2,923,158	476,379	3,399,537
Cash (outflow)/ inflow	(87,483)	(286,019)	(373,502)
Balance as at 31 March 2022	2,835,675	190,360	3,026,035

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 2021

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

14 Liabilities

	2022 £	2021 £
Research grants not yet claimed	1,968,529	1,906,098
Accruals	13,589	16,672
Other creditors	24,911	33,921
Due within 12 months	2,007,029	1,956,691
Research grants due after 12 months	2,944,516	2,392,181
	4,951,545	4,348,872

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 2022 £
Balance as at 1 April 2021	1,042,684	900,859	1,943,543
Net incoming resources	-	694,945	694,945
Transfer between funds	695,804	(695,804)	-
Balance as at 31 March 2022	1,738,488	900,000	2,638,488

Unrestricted Funds 2021

	Designated Research Fund £	General Fund £	Total 2021 £
Balance as at 1 April 2020	1,494,579	988,645	2,483,224
Net incoming 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

16 Restricted Funds

	1 April 2021 £	Incoming Resources £	Resources Expended £	31 March 2022 £
Research Grants	-	499,331	(499,331)	-
Shape Network	21,000	94,000	(47,618)	67,382
Celine Newman prize	6,360	-	(500)	5,860
	<u>27,360</u>	<u>593,331</u>	<u>(547,449)</u>	<u>73,242</u>

Restricted income for research grants relates to:

Prof M Cousin	£600	
Dr C Tye	£13,412	Joint project with Autistica
Dr C Tye	£72,770	
Dr B Diehl	£72,770	
Dr W Woldman	£72,770	
Prof N Dale	£72,770	
Dr G Morris	£68,782	
Prof M Walker	£72,770	
Dr S Vos	£52,687	
	<u>£499,331</u>	

All of the research listed above was funded in previous years and is shown in the accounts as a transfer from restricted funds to unrestricted funds. The Shape Network is a community of people affected by epilepsy who are dedicated to influencing research. The Celine Newman Prize represents an award made annually for Neurobiology of Epilepsy.

Restricted Funds 2021

	1 April 2020 £	Incoming Resources £	Resources Expended £	31 March 2021 £
Research Grants	-	71,000	(71,000)	-
Shape Network	-	21,000	-	21,000
Celine Newman prize	6,960	-	(600)	6,360
	<u>6,960</u>	<u>92,000</u>	<u>(71,600)</u>	<u>27,360</u>

17 Analysis of Net Assets between Funds

	Unrestricted Funds 2022 £	Restricted Funds 2022 £	Total Funds 2022 £
Total Assets	7,590,033	73,242	7,663,275
Current liabilities	(2,007,029)	-	(2,007,029)
Creditors falling due after more than 1 year	(2,944,516)	-	(2,944,516)
	<u>2,638,488</u>	<u>73,242</u>	<u>2,711,730</u>

Analysis of Net Assets between Funds 2021

	Unrestricted Funds 2021 £	Restricted Funds 2021 £	Total Funds 2021 £
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>

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. No grants were awarded in 2022 to Trustees, although some had connections to the institutions. 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.

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

	2022 £	2021 £
Net Inflow/(Outflow) in funds	740,827	(519,281)
Deduct Investment income shown in investing activities	(86,119)	(64,741)
Deduct investment gain/add (loss)	(20,557)	(253,089)
(Increase)/Decrease in debtors	(131,443)	523,362
Increase/ (Decrease) in creditors due within 1 year	50,338	403,251
Increase/(Decrease) in creditors due after more than 1 year	552,335	325,076
Net cash used in operating activities	1,105,381	414,578

20 Statement of Financial Activity for the year ended 31 March 2021 (prior year)
(Including the Income & Expenditure Account)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Income from:			
Donations and legacies	1,020,408	92,000	1,112,408
Charitable activities research grants not required	32,635	-	32,635
Other trading activities	16,495	-	16,495
Investments	64,741	-	64,741
Total Income	1,134,279	92,000	1,226,279
Expenditure on:			
Raising Funds	158,935	-	158,935
Charitable Activities:			
Research grants committed	1,297,966	23,000	1,320,966
Other charitable activities	518,148	600	518,748
Total Charitable Activities	1,816,114	23,600	1,839,714
Total Expenditure	1,975,049	23,600	1,998,649
Net unrealised Gains/(Losses) on investments	253,089	-	253,089
Net Income/(Expenditure) for the year	(587,681)	68,400	(519,281)
Transfers between funds	48,000	(48,000)	-
Net Movement in Funds for the year	(539,681)	20,400	(519,281)
Reconciliation of Funds:			
Total funds brought forward on 1 April 2019	2,483,224	6,960	2,490,184
Total funds carried forward at 31 March 2020	1,943,543	27,360	1,970,903

Epilepsy Research UK

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Registered charity number 1100394