EPILEPSY RESEARCH INSTITUTE UK

England & Wales · Charity number 1100394

Details

Other names	EPILEPSY RESEARCH FOUNDATION, EPILEPSY RESEARCH UK, FUND FOR EPILEPSY
Status	Registered
Legal form	Charitable company
Company number	04873718
Registered	2003-10-30
Register	View on the Charity Commission register

Contact

Address	82 Tanner Street London SE1 3GN
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Website	www.epilepsy-institute.org.uk

Activities

Objects: 1. TO PROMOTE, ENCOURAGE AND FINANCE RESEARCH INTO EPILEPSY AND ASSOCIATE DISEASES AND THEIR UNDERLYING CAUSES;2. TO PROMOTE AND IMPROVE THE TREATMENT CARE AND WELFARE OF PERSONS AFFECTED FROM EPILEPSY AND ASSOCIATED DISEASES; AND 3. TO ADVANCE THE GENERAL EDUCATION AND UNDERSTANDING OF THE PUBLIC CONCERNING THE NATURE AND CAUSES OF EPILEPSY AND ASSOCIATED DISEASES AND THE TREATMENT THEREOF.

Activities: The Epilepsy Research Institute serves as the central hub for the epilepsy research community. The Institute aims to strengthen the epilepsy research ecosystem . Prior to becoming the Institute in 2023, it was Epilepsy Research UK which was formed by the merger of the Epilepsy Research Foundation and the Fund for Epilepsy in April 2007.

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Classification

- **How:** Makes Grants To Organisations, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities, The General Public/mankind

Geography

- **Area of benefit:** NOT DEFINED. IN PRACTICE EUROPE
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£1,700,383	£2,855,052	£3,067,872	14
2024-03-31	£3,595,109	£3,091,263	£4,178,272	10
2023-03-31	£3,605,370	£2,658,426	£3,395,584	10
2022-03-31	£2,987,008	£2,266,738	£2,711,730	8
2021-03-31	£1,226,279	£1,998,649	£1,970,903	8

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Trustees

Name	Role	Appointed
Anna Louise Prideaux		2025-09-25
Jane Elizabeth Cullinan Beaven		2025-11-12
Juliet Kate Solomon		2023-12-14
Lesslie Anne Young		2023-12-14
Marilyne Kekeli Abony		2026-07-03
Nicholas John Bennett		2026-07-03
Professor Anthony Marson		2023-03-22
Professor Mark Richardson		2013-09-18
Professor Martin John Elliott		2022-06-30
Professor Matthew Walker		2011-10-19
Professor Michael Alan Cousin		2020-06-17
Professor Nicholas John Lench		2021-09-15
Rebekah Smith		2023-12-14
Simon Lodge		2024-12-12

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EPILEPSY RESEARCH INSTITUTE UK

England & Wales - Charity number 1100394

Accounts

STRENGTHENING THE EPILEPSY RESEARCH ECOSYSTEM

Annual Report 2024-2025

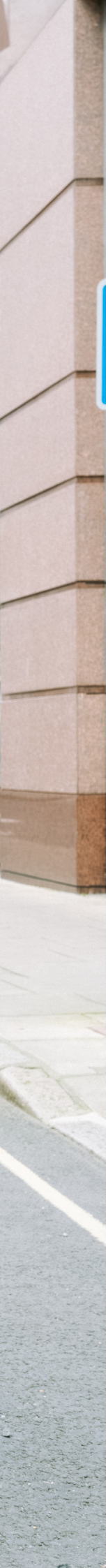


EPILEPSY RESEARCH INSTITUTE UK

epilepsy-institute.org.uk



"For me, hope came in the form of research. At the age of 15, I took part in a groundbreaking project by Dr Antonio Valentin, which changed my life. Thanks to this research, I have since been seizure-free for 10 years."- Sophie, Epilepsy Research Institute Supporter



CONTENTS

Page 4	Our Year in Numbers
Page 6	Welcome from our Chair and Chief Executive
Page 8	Our Inaugural Conference
Page 10	Our Mission, Vision and Values
Page 11	The Epilepsy Landscape and Global Perspective
Page 12	Our Research Programme
Page 14	Building and Strengthening the Epilepsy Research Community
Page 16	Convening and Connecting the Research Community
Page 18	Our Partnerships
Page 20	Our Research Awards
Page 26	Two New Publications Set Out our Vision
Page 28	The Shape Network
Page 30	The One in 100 Campaign
Page 32	The People Behind the Numbers
Page 34	Our Research Outcomes
Page 36	Our Amazing Supporters
Page 40	Trustees' Report and Financial Statements

OUR YEAR IN NUMBERS

FUNDING

£1.71 million

Invested in our 2025 Research Awards

327

Institute supporters took on challenges to raise money for vital research raising nearly £300,000



MEMBERS

770

researchers signed up to 'The Hub' – our online portal for researchers working in the field of epilepsy and associated conditions

Over 690

people now part of the Shape Network – the UK's largest network of research-interested people affected by epilepsy

SHAPE NETWORK

PARLIAMENTARY WORK



405

MPs contacted about epilepsy research

5

written parliamentary questions tabled

19 MPs

signed up as One in 100 campaign champions

RESEARCH



The Epilepsy Research Institute is supporting

40

active research projects across

18

institutions, involving over

100

researchers and collaborators in the UK and internationally



WELCOME FROM OUR CHAIR AND CHIEF EXECUTIVE



Professor Matthew Walker
Chair of Trustees



Rosemarie Pardington
Chief Executive

Since our formal launch as the Epilepsy Research Institute in October 2023, we have embarked on a transformative journey. Born from an unprecedented collaboration across the whole epilepsy community, our goal has been clear from the start: to radically advance research into epilepsy by uniting a research landscape that has for too long been fragmented.

Last year, we spoke of the need to invest in the structure and foundations of the Institute – and, as this report demonstrates, we have made significant progress on this front. We've brought together stakeholders from across the epilepsy community and together developed a shared vision. In addition, we have identified the research challenges we must address if people with epilepsy are to reap the benefits of scientific progress.

This year, we have taken the liberty in our annual report to include a few events that took place just outside the usual 12-month period, as all the planning and preparation was done within this financial year, it seemed prudent to do so. One particularly significant milestone for the Institute this year has been the development and publication of our organisational **Strategic Plan for 2025-2030.** This five-year plan outlines our ambitious goal to secure £110 million for epilepsy research by 2030. We'll achieve this through targeted fundraising, funding partnerships and strategic leveraging.

The strength of the Institute lies in the networks we have established with key stakeholders across the health, research and academic ecosystem. Based on the top ten research priorities, set by the epilepsy community, our theme leads, and Taskforce members have worked diligently to clarify their aims and identify research gaps and priority questions to take these areas forward. These have been published in the **Research Roadmap** document which underpins our strategic plan.

Together, these two documents, define the strategic direction of the Institute and we were delighted to see them published.

Already we're seeing momentum build. The networks we convene are going from strength to strength. We now have over 770 academics signed up to The Hub, interested to find out more about funding, patient involvement in research and collaboration opportunities. While the majority of members are currently based in the UK, the network is international and already includes individuals from 37 countries. Recently, we launched the first iteration of our **Researcher Directory** on our website which profiles

researchers working in epilepsy from around the world, helping the community connect with experts and potential collaborators. We'll be growing the directory over the coming year and inviting those who want to create their own profile to join this impressive lineup.

In the past year, we've **hosted two Navigator Symposiums**. These events bring scientists together to share insights, spark new ideas, and foster national and international collaboration. They have become increasingly popular within the community, so we plan to continue offering them in the future.

We also **held an Industry roundtable** with representatives from a number of pharmaceutical and technology companies to explore existing and emerging partnership models. Moving into year one of our strategic plan, we look forward to taking these relationships forward, recognising it is only by working together with industry that we can unlock the level of investment required to radically advance research that will change the lives of people with epilepsy.

The **continued growth of our Shape Network** – the UK's largest group of research-interested people affected by epilepsy – is something we are truly proud of. The network now has over 690 members, all with personal experience of the condition. It continues to provide a much-valued resource for researchers to ensure the voices of people with epilepsy are shaping their work.

After months of planning and preparation, in May we held our inaugural conference, at which we were thrilled to announce new funding through our 2025 Research Awards and confirm our commitment to **invest a further £1.71m into research,** supporting Entry and Emerging Leader Fellowships and Endeavor Projects Grants. As you will read later in this annual report, these new awards fund an outstanding range of innovative projects and rising stars.

Raising awareness of epilepsy is one of our three strategic goals. Without it, we cannot increase research investment from government and other funders. This is why we **launched our One in 100 Campaign** in October last year to highlight the costs to society and shocking statistics, including, tragically, that there are three epilepsy-related deaths every day in the UK alone. As a result of our campaign, over 400 people have now written to their MPs. So far, 19 MPs have signed up as campaign champions and we have had five written parliamentary questions tabled on epilepsy research. Our One in 100 appeal is helping us begin to raise the essential funds needed to advance epilepsy research.



We have another busy and ambitious year in front of us. We'll be pressing on with new national and international partnerships focused on priority areas that have been identified by or complement the work of our Theme leads and Taskforce members. In addition to our annual grant round and vital work to convene and connect the community, we'll be launching new strategic partnerships to improve the epilepsy research infrastructure. We continue to engage with industry, government and charitable funders to ensure that epilepsy research attracts and secures the investment required to drive meaningful and transformative progress.

Of course, none of this would have been possible without the generous support from our Founding Partners, supporters, volunteers, colleagues and partners who have continued to contribute to our success over the past year and we are immensely grateful to each and every one of them.

OUR INAUGURAL CONFERENCE

The inaugural Epilepsy Research Institute Conference took place during National Epilepsy Week 2025, bringing together leading researchers, clinicians, early-career scientists and those with lived experience of epilepsy for two days of groundbreaking discussions and collaboration.

Held in Manchester, the conference showcased the Institute's ambition to radically advance epilepsy research. From molecular neuroscience to global patient needs, the event reflected the urgent need for innovation in tackling one of the most common but under-researched and under-funded neurological conditions.

This ambitious event offered a valuable opportunity for knowledge-sharing and was well attended —achieving its goal of breaking even, and also generating a small but welcome contribution to our research fund.





Day 1

Highlights of the day included:

- A compelling keynote from Professor Ivan Soltesz (Stanford University), who shared cutting-edge insights into neuronal microcircuits, highlighting how advances in basic neuroscience are opening new pathways for monitoring and treating epilepsy.
- Fascinating presentations and parallel sessions on the Institute's strategic research themes: Neurodevelopment, Mortality, Morbidity & Risk, Advanced Therapeutics & Disease Modification, Reproduction & Hormones, Capacity Building and Enabling Technologies.
- A celebratory dinner which included the announcement of the 2025 Research Awards (see page 20 to read more about these).
- A special screening of the short film Under the Lights, followed by a live Q&A with filmmaker Miles Levin, who lives with epilepsy.





Day 2

Highlights of the day included:

- A session titled 'The Power of Partnership' featuring members of the Institute's Shape Network – Emma, Murray and Kathryn – who highlighted the critical importance of involving people affected by epilepsy in shaping research priorities. This was followed by Dr Claire Nolan (International Bureau for Epilepsy) presenting findings from the Global Epilepsy Needs Study.
- A second keynote delivered by Laureate Professor Ingrid Scheffer (University of Melbourne), a global leader in epilepsy genetics, exploring how gene discovery has revolutionised our understanding of epilepsy syndromes and opened new therapeutic pathways.
- A celebration of research excellence, recognising standout contributions across oral and poster presentations. Awards were given for innovation, clarity and impact – highlighting the talent driving epilepsy research forward.

Professor Helen Cross OBE, President of the Epilepsy Research Institute, closed the conference, praising the spirit of collaboration and the calibre of innovation on display and celebrating the progress achieved by the Institute in such a short period of time.







Thank you to our sponsors

The Epilepsy Research Institute would like to thank our generous sponsors:
ILAE British Branch, UNEEG Medical, UCB, Epilepsy Action, Neuronostics, Matthew's Friends and Cardonet, for their generous support which enabled this impactful conference to take place.

OUR VISION, MISSION AND VALUES

Our Vision
A life free from epilepsy

Our Mission
To radically advance research into epilepsy

Our Values

INTEGRITY	We are open and transparent about all aspects of our work and employ the utmost candour in our focus to '*radically advance research into epilepsy*'.
COLLABORATIVE	We appreciate that it is only by working together we will achieve our vision of '*a life free from epilepsy*'. Our teamwork and partnerships reflect our integrity, professional approach and trustworthiness.
HONESTY	We expect a high standard of excellence, supporting the best science with our systematic and rigorous approach to all of our work.
INNOVATIVE	We are courageous and ambitious to enable ground-breaking research and welcome innovative and creative ideas.
DIVERSITY & INCLUSION	We are respectful of all the people working with, and for us, including people living with epilepsy, researchers, collaborators and our supporters, fostering teams across diverse cultures and backgrounds and valuing their views and input.

Our Founding Partners

EPILEPSY ACTION · epilepsy scotland · ILAE International League Against Epilepsy · Young Epilepsy

THE EPILEPSY LANDSCAPE AND GLOBAL PERSPECTIVE

Epilepsy affects over 630,000 people in the UK, with over 29,000 being newly diagnosed each year. There are also three lives lost every day due to epilepsy related deaths — a mortality rate higher than some other developed nations.

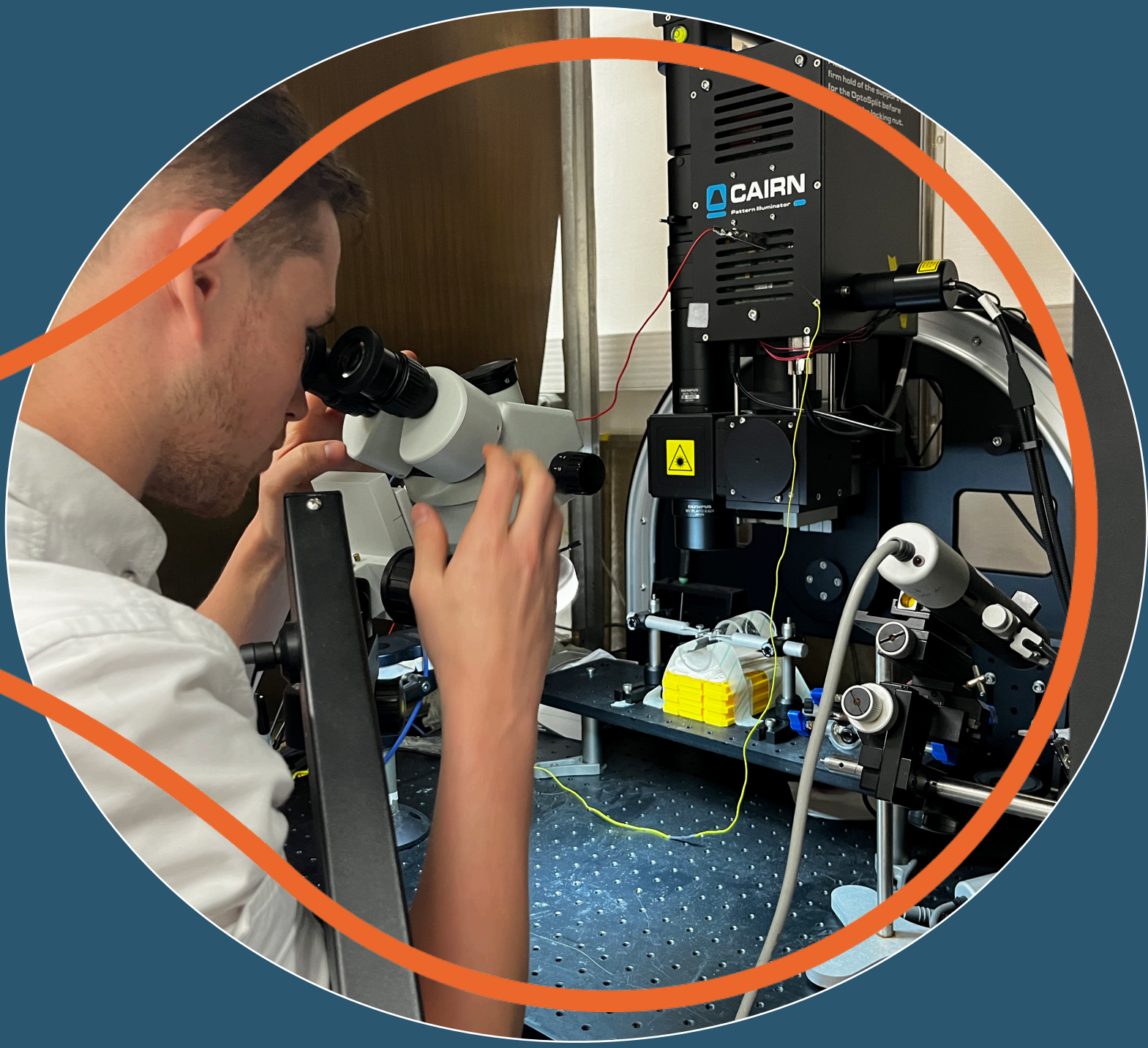
Every year the condition drives 100,000 UK hospital visits and accounts for 1% of all NHS costs, yet stark health inequalities continue to prevent many from accessing timely support. As the Government sets about reforming the NHS, this cost is something that must be urgently addressed.

In addition to the direct impact of epilepsy itself, people with the condition also have a significantly increased risk of experiencing mental ill health. However, the impact extends far beyond physical and mental healthcare. Epilepsy disrupts education, limits employment opportunities, and places immense strain on carers. The total economic burden of epilepsy is far in excess of £2 billion per year. Idiopathic epilepsy alone costs the UK £1.7 billion annually (0.07% of the UK's 2019 GDP), with lost productivity accounting for more than half of this cost. Given its wide-reaching consequences, epilepsy research must therefore be a national priority.

Worldwide, over 50 million people live with epilepsy, with nearly 80% of reported cases being in low- and middle-income countries where inadequate healthcare leads to higher mortality rates. Recognising this global challenge, the World Health Organisation (WHO) issued a bold call to action with its ten-year 'Intersectoral Global Plan' (IGAP) for epilepsy and other neurological disorders.

This important plan urges governments, funders, and researchers to work together to improve the lives of those with these conditions. As populations around the globe continue to age, there will also emerge various challenges and opportunities relating to the delivery of optimal epilepsy healthcare to senior citizens who are at increased risk of a first diagnosis.

OUR RESEARCH PROGRAMME



To realise the Institute's vision of a life free from epilepsy, we are committed to fundamentally transforming the epilepsy research ecosystem. We're uniting the myriad stakeholders involved in epilepsy research behind a shared scientific strategy. These priorities are set out in our Research Roadmap, published at the end of 2024 (see page 27). It focuses on our six research themes that are underpinned by the needs and priorities of people affected by epilepsy.

Each theme continues to be overseen by three co-leads and is now supported by a taskforce of international scientists, clinicians, industry partners, and Shape Network members. Over the past year, these taskforces—supported by the Institute's research team—have defined key aims to drive progress towards our strategic objectives.

There have been extraordinary advances in epilepsy research over the past few years, but sadly it remains underfunded given the prevalence and impact of the condition. To change this, we are building connections with researchers and funders in adjacent fields such as stroke and dementia, where there is a strong rationale to be joining forces to add value and impact .

BUILDING AND STRENGTHENING THE EPILEPSY RESEARCH COMMUNITY



To drive meaningful progress in epilepsy research, we recognise the need to attract promising early-career researchers committed to making epilepsy their focus, while also supporting high-calibre established researchers to stay in — or bring fresh expertise into — the field.

Our funding awards help shore up the next generation of epilepsy experts. Meetings and workshops bring people together to share knowledge, spark discussion and promote collaborations. Our research community has described other ways we can help build capacity, too.* We have started to develop some of these ideas through our Capacity Building Theme. The following paragraphs illustrate just a few of these initiatives:

Fellowships for future epilepsy research leaders

Funding fellowships to allow early career researchers to develop specific research and leadership skills and collaborations is one of our core activities. Through these funding awards, we are proud to have supported 29 Fellows since 2009, with 19 fellowship projects ongoing. Furthermore, 80% of researchers who have completed an Institute-funded fellowship are still active within epilepsy research.

You can read about the cutting-edge research projects being undertaken by our 2025 Fellows on pages 20–25.

*Capacity building survey results 2024 and in-person responses, Emerging Leaders Symposium, May 2024.

Enthusing and empowering researchers

Our Navigator Symposia showcase the best epilepsy research in different – and often understudied – areas, highlighting groundbreaking findings and the research questions that arise.

Developed and hosted by an Institute Fellow and senior researcher, each Navigator Symposium brings together established and early career researchers from across the UK and beyond. We have been delighted to stage recent symposia on:

- Data Science and Translation in Epilepsy, with Dr Wessel Woldman (University of Birmingham) and Professor Peter Oliver (MRC Nucleic Acid Therapy Accelerator), in partnership with N-CODE
- Reproduction and Neurodevelopment in Epilepsy, with Dr Amy Richardson (University College London) and Professor Laura Andreae (King's College London)

"It really inspired me to explore new questions that might be included in my future research plans."
Navigator Symposium attendee

Strengthening networks

Our academic and clinical epilepsy community value opportunities to meet and discuss their research, whether in local or regional research groups or more specialised networks. These opportunities help individuals sense check and develop their research ideas and access different spheres of expertise. However, some researchers and clinicians have limited opportunities to meet locally, as no group or network exists.

Our Capacity Building Theme Leads, supported by their Task Force, have developed a programme of work to support and maintain epilepsy networks. A 'Networking for Networks' meeting, in Spring 2025, brought together speakers and attendees to share their experience of running successful networks and meetings. Best practice recommendations, developed from this meeting, are now available to help those wanting to establish and run a network, and the Institute is about to pilot small awards to help with the initial meeting costs to establish new networks.

"A well-supported epilepsy research network fosters the development of innovative treatments, enhances clinical care pathways, and advances public understanding. By centring on collaboration and community engagement, it builds a research ecosystem that delivers meaningful impact for people living with epilepsy."
- PhD student

Support from the start

Early in their careers, researchers are eager to seize every opportunity to learn, grow and refine their skills. We are delighted to be launching a pilot scheme to support early career researchers to attend epilepsy conferences and training courses that they might otherwise have to miss. By helping younger scientists expand their knowledge of epilepsy research and build essential skills at this formative stage, we are laying strong foundations for a thriving, high-quality research community.

CONVENING AND CONNECTING THE RESEARCH COMMUNITY

Epilepsy Research Institute task force groups

Over the past year, the Institute's six strategic research themes clarified their ambitions in the 2024 Research Roadmap, laying the groundwork for a coordinated programme of activity designed to drive bold progress in epilepsy research.

Each theme has convened a task force to steer and influence the development and delivery of activities. Task force members include researchers, healthcare professionals, patient organisations, people affected by epilepsy, funders and regulators.

Delivering focused theme workshops

During our inaugural conference, the Institute's core research themes held workshops bringing together researchers, clinicians and people affected by epilepsy to identify knowledge gaps and explore research into epilepsy across the following four broad areas:

Mortality, Morbidity & Risk theme

The cardiovascular health of people with epilepsy is a growing concern. As people with epilepsy get older, they are at greater risk of experiencing cardiovascular problems. The theme leads convened a workshop that brought together basic and clinical researchers to share their insights and identify important priorities to further develop this work. They plan to produce a paper that shares the important unknowns around cardiovascular health, with the goal of ultimately reducing rates of mortality and morbidity in epilepsy.

Reproduction & Hormones theme

We currently know very little about the reciprocal relationship between reproductive hormones and epilepsy in women and men. We held a workshop that brought together experts and early career researchers from across the world to identify research gaps and advance our knowledge in this area. As a result, the theme leads plan to produce a collaborative call-to-action paper with recommendations and next steps to advance research on the relationship between reproductive hormones and epilepsy.

Neurodevelopment theme

The lack of meaningful biomarkers to support diagnosis, monitoring and to assess outcomes in clinical trials is a major gap. A highly regarded group of speakers and panel members provided updates on developments in their research areas: early developmental markers in children with epilepsy, and neuropsychological assessment in adults; MRI; EEG; and using AI and machine learning with multiple biomarkers to increase the specificity and sensitivity of tests. Insights from the presentations and subsequent discussions will inform biomarker-related activities in our future work programme.

Advanced Therapeutics & Disease Modification theme

"Bottlenecks to moving from laboratory to clinical use" was the theme of the Advanced Therapeutics and Disease Modification workshop. Researchers at all career stages contributed to interactive sessions to identify issues and opportunities around preclinical models, accelerating clinical trials, the delivery of therapeutics to the brain, and commonalities between different epilepsies. The outputs will be used to develop academic papers to raise awareness, promote discussion and support researchers' interactions with funders and regulators.



Workshop: advancing SUDEP research

Each week in the UK, at least 21 people die from epilepsy-related causes, many classified as Sudden Unexpected Death in Epilepsy (SUDEP). In 2022, our Priority Setting Partnership identified epilepsy-related deaths, including SUDEP, as the top research priority.

We hosted a multidisciplinary workshop in September 2024 to identify and address gaps in lab-based and clinical SUDEP research. The key outcomes, including research priorities and recommendations, are now published in the American journal Epilepsy & Behavior.

Several recommendations were made, including:

- Supporting lab-based research through international collaborations and bringing in expertise from fields such as cardiovascular and respiratory science.
- Urgently advancing our understanding of the common mechanisms underlying SUDEP.
- Investigating how risk information can be delivered to patients more effectively.
- Identifying and tracking risk factors and how these change throughout the life course.
- Developing infrastructure to support the optimisation of epilepsy patient data to drive forward research efforts in this field.

In a joint statement, the Mortality, Morbidity & Risk theme leads, Professor Arjune Sen, Dr Rob Wykes and Dr Amol Bhandare, said:

"There are still so many unanswered questions about why SUDEP happens and how it can be prevented. This workshop brought together a diverse group of experts and people personally affected by SUDEP. We identified several knowledge gaps that can now be addressed through collaborative research. Our hope is that we can explore these gaps to better understand SUDEP risk and develop strategies to reduce this risk in both the short and long term."

Engagement with the wider research community, as well as broader stakeholders, including people with epilepsy, charities, healthcare professionals and government bodies, will be essential in the further development and implementation of these recommendations.

OUR PARTNERSHIPS

Strategic partnerships and collaborations

To make the radical progress we're striving for, we need to work with partners from across the life sciences sector to raise the profile of epilepsy research, promote innovation and ultimately drive strategic investment. This includes UK-based and international epilepsy organisations, industry, government funders, partners working in adjacent health disciplines and of course people living with and affected by epilepsy.

Partnering with industry to unlock progress

The Institute has had an established strategic alliance with Rome-based pharmaceutical company Angelini Pharma since 2022.

This year we're delighted to continue the alliance with Angelini and announced a £200,000 funding extension to the project enabling data-driven research at King's College London in collaboration with Health Data Research UK. The continued funding will expand the study to analyse 30,000 patient records and to further refine and test their AI hypothesis.

Agnese Cattaneo, Angelini Pharma's Global Chief Medical Officer, said, "One-third of people with epilepsy still experience seizures despite treatment, highlighting the urgent need for new insights. At Angelini Pharma, we are proud to support this AI-driven research to uncover key risk factors and advance personalised treatments. This extension brings us closer to transforming patient care."

Broadening our engagement with industry

Our successful industry roundtable brought together senior representatives from 16 companies spanning the pharmaceutical, biotech and health technology sectors to strengthen our partnership offer to industry. We discussed key challenges in the delivery of clinical research and in the translation of innovation into the NHS, exploring ways to bring forward collaborative solutions. The event marked the start of an ongoing conversation with several future partners which we hope to progress in the coming year.



Advancing the agenda for SUDEP research

We are working in partnership with SUDEP Action, CURE Epilepsy and Partners Against Mortality in Epilepsy (PAME) to stimulate impactful research into the causes and prevention of sudden unexpected death in epilepsy (SUDEP). In 2024 we committed to co-funding a SUDEP-focused Emerging Leader Fellowship in partnership with SUDEP Action with a call planned for fellowship applications in the 2025/6 grant round.

Following our SUDEP workshop in September 2024, and recent publication in collaboration with SUDEP Action (see page 17), we're now joining forces with CURE Epilepsy and PAME in the US to develop a shared call to action to prioritise and address key research questions related to SUDEP.

Collaboration in Late-Onset and Vascular Epilepsy Research – CLOVER

Late-onset epilepsy is fast becoming the most prevalent form of the condition, but it is a neglected research area, especially the links between late-onset and vascular epilepsy and conditions such as stroke and dementia.

In partnership with the Institute, Collaboration in Late-Onset and Vascular Epilepsy Research (CLOVER - led by Professor Hedley Emsley and Dr Sana Hannan at Lancaster University, in collaboration with Dr Clare Gordon at University of Central Lancashire) is bringing together interested people with epilepsy, researchers and clinicians to identify research priorities and stimulate new collaborations to move research forward into the interplay between epilepsy, cerebrovascular disease and neurodegeneration. There will be a series of workshops to develop and produce a research roadmap and establish a sustainable network to support future research.

CLOVER
COLLABORATION FOR LATE-ONSET AND VASCULAR EPILEPSY RESEARCH

UK Dementia Research Institute

UK Dementia Research Institute

During 2024 our series of joint workshops with Dementia Research Institute (UKDRI) focused on exploring the biological overlap between Alzheimer's disease and epilepsy to identify where future research must focus. Uniting the two fields is stimulating new ideas and collaborations, such as with our new Entry Fellowship recipient, Dr Francesca Chaloner, who works at the UKDRI and will be investigating whether a non-invasive brain stimulation technique can treat Alzheimer's related epilepsy (see page 22).

Joint working with our founding partners

The Epilepsy Research Institute was established with the support of leading UK epilepsy charities, who continue to contribute through their role as founding partners: Epilepsy Action, Epilepsy Scotland, Young Epilepsy and the International League Against Epilepsy (British Branch) who are all part of our Trustee Board and provide a much-valued contribution.

Joint Roundtable Event with Epilepsy Scotland

epilepsy scotland

On 4 October 2024 we held a joint event with Epilepsy Scotland, to explore opportunities for greater collaboration. We wanted to provide the forum for the epilepsy-interested research community from across Scotland to come together with the Institute to enable us to work together more cohesively and consider any new joint initiatives.

This event provided everyone with an introduction to the Institute and the opportunities it offers researchers across the UK, and for our Scottish colleagues to share expertise and experience.






OUR RESEARCH AWARDS

This year's Grant Round included something for everyone to apply for:

- Our flagship Emerging Leader Fellowships, to secure promising early career researchers a future in epilepsy research
- A brand-new Entry Fellowship, for researchers just out of a PhD and looking to develop their niche
- Our Endeavour Project Grants, for established researchers with an exciting new idea

Our 2024-25 Grant Round kicked off in summer 2024, when researchers were invited to submit a preliminary application, briefly outlining their idea, aims, and collaborators. These preliminary applications were then assessed and shortlisted by the Institute's Scientific Advisory Committee (SAC), a panel of the UK's leading neurologists, neuroscientists, and epilepsy researchers.



Shortlisted applicants were invited to an 'Application Clinic' with members of the Shape Network (which you can read more about on page 28).

The Institute is proud to be a member of the Association for Medical Research Charities (AMRC). To maintain our membership, the Institute has to demonstrate it follows the AMRC's rigorous standards in peer review, enabling us to ensure the research we fund is of the highest quality. We are also obliged to publish our research strategy and meet other requirements for this important membership.

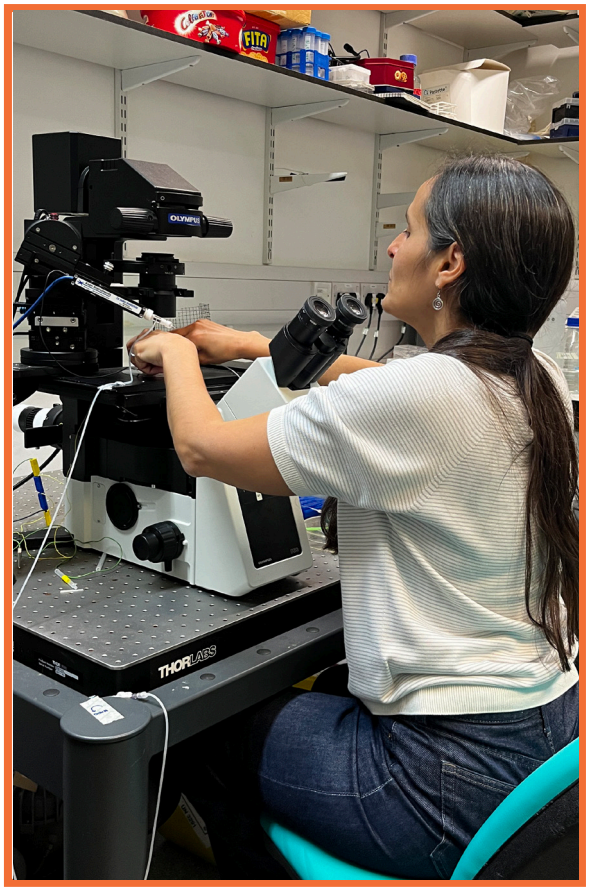
Following submission, applications were evaluated by Expert Reviewers – independent academics and clinicians with experience and skills relevant to the application. Applicants have a chance to provide a rebuttal to the expert reviewer scores and comments.

Left: Entry Fellowship winner, Dr Francessca Chaloner

After this, the applications go back to our SAC. They read through all the full applications, Shape Network feedback, Expert Reviewer comments, and the applicant rebuttals. Taking all of this into account, the SAC thoroughly discussed each of the Endeavour Project applications and submitted new scores. The top-ranked projects were then recommended for funding.

After such a thorough and rigorous process, it's incredibly rewarding that the Epilepsy Research Institute is investing over £1.51 million pounds in eight new cutting-edge research projects with the potential to transform the lives of people living with epilepsy.

Professor John Duncan, Chair of the Scientific Advisory Committee, said: "We're excited by the range of grants we are funding this year, from investigating the underlying mechanisms of epilepsy and seizures, to improving the detection and diagnosis of epilepsy, to developing the treatments of tomorrow."



Right: Emerging Fellowship winner, Marisol Sampedro Castañeda

We are so appreciative of our Expert Reviewers, Shape Network members, and our SAC for their commitment to helping us to find the most promising research applications to fund.

You can read more about this year's grants on the following pages. We look forward to seeing the results from these projects and the real-world impact they will have.

In addition to the new awards funded within the grant round, an extension to the project 'Natural Language AI to identify predictors of refractory epilepsy in NHS Electronic Health Records', led by Professor Mark Richardson of Kings College London was awarded £199,913 funding. This sixteen month project extension represents a continued partnership with Angelini Pharma.

In total the Institute funded over £1.71 million of research awards in 2024-25.



RESEARCH AWARDS 2025



Can non-invasive brain stimulation treat Alzheimer's Disease related epilepsy?

GRANT TYPE: Entry Fellowship
GRANT AMOUNT: £97,024
LEAD INVESTIGATOR: Dr Francesca Chaloner
CO-INVESTIGATORS: Dr Samuel Barnes, Professor Michael Johnson
INSTITUTION: Imperial College London

BACKGROUND

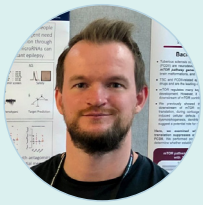
Epilepsy is 2-3 times more common in people with Alzheimer's disease (AD) than in the general population and can make cognition worse. Few studies have investigated the link between these two diseases and the mechanisms underlying this link is unknown.

THE STUDY

This study will use a new animal model that shows signs of both epilepsy and Alzheimer's disease. Francesca will measure brain activity using a technique that records electrical signals (like EEG) and shows how brain cells work together. She will also test a new type of non-invasive brain stimulation, called 'Temporal Interference', which can target deep brain areas without affecting surrounding tissue. The technique is already being tested in people with Alzheimer's and may help reduce seizure activity. The study will also examine how this brain stimulation affects specific types of brain cells linked to both conditions.

SIGNIFICANCE

The research will help explain why people with Alzheimer's are more likely to have epilepsy. It will also test a promising new treatment that could reduce seizures and improve brain health. If successful, this approach could be quickly tested in people, offering a new option for those living with both epilepsy and Alzheimer's.



A novel advanced therapy to treat epilepsy by directly targeting the underlying mechanisms

GRANT TYPE: Endeavour Project Grant
GRANT AMOUNT: £173,770.42
LEAD INVESTIGATOR: Dr Gareth Morris
CO-INVESTIGATOR: Professor Susan Kimber
INSTITUTION: University of Manchester

BACKGROUND

Current treatments for epilepsy often rely on daily medication, which can cause significant side effects and are not always effective. Genetic therapies could offer long lasting and potentially curative alternatives. These treatments aim to correct or block underlying biological mechanisms that causes seizures, rather than simply managing symptoms. Recent work using human brain tissue from people with epilepsy has identified a molecule called a microRNA that may disrupt the brain's natural ability to stop seizures. Understanding and targeting this molecule could lead to a breakthrough in how epilepsy is treated.

THE STUDY

This study will develop a new genetic therapy to block the effects of this specific microRNA found in epileptic brain tissue. This microRNA appears to interfere with the brain's natural inhibitory signalling – the system that normally helps to stop seizures by 'putting the brakes' on overactive brain cells. By developing a therapy that can block this microRNA, Gareth's work aims to restore this natural protection and reduce or prevent seizures.

SIGNIFICANCE

A successful genetic therapy would provide a long lasting option for people with drug resistant seizures. As a relatively recent discovery, microRNAs represent a new focus in epilepsy research, and this study will improve our understanding of how microRNAs contribute to epilepsy.



Is valproate safe to use in men if they wish to have children?

GRANT TYPE: Endeavour Project Grant
GRANT AMOUNT: £148,434.03
LEAD INVESTIGATOR: Dr Craig Heath
CO-INVESTIGATORS: Professor Colin McCowan, Dr Rebecca Bromley, Dr John Craig, Dr Alex Marshall
INSTITUTION: NHS Greater Glasgow and Clyde

BACKGROUND

Valproate is one of the most effective anti-seizure medications, particularly in people who develop epilepsy during adolescence. However, concerns about its possible impact on child development and risk of birth defects have led to strict prescribing regulations. The UK's medicines regulator has introduced restrictions for men taking valproate, despite limited evidence to support this, so research is urgently needed to understand whether paternal use of valproate affects children's development.

THE STUDY

This study will use anonymised health data in Scotland to examine whether children born to fathers who take valproate are at increased risk of developmental delays or major birth defects. Thanks to recent advances in data science, it's now possible to accurately link children to their fathers, allowing the team to compare outcomes in children with paternal exposure to valproate against those without such exposure.

SIGNIFICANCE

This study will provide vital evidence about the safety of valproate use in men of reproductive age, helping guide treatment decisions for men with epilepsy who are planning a family. More broadly, the study will add to our understanding of how the impact of paternal medication use may affect child health and development, supporting safer prescribing practices and robust policy in the future.



What cellular processes help to stop seizures?

GRANT TYPE: Endeavour Project Grant
GRANT AMOUNT: £174,700
LEAD INVESTIGATOR: Professor Andrew Trevelyan
INSTITUTION: Newcastle University

BACKGROUND

Most seizures stop without any medical help. This suggests that the brain has natural anti-seizure mechanisms, but we still do not fully understand these. One possible explanation is a phenomenon called cortical spreading depression (CSD). However, while CSD may help end seizures, it has also been linked to SUDEP (sudden unexpected death in epilepsy). Understanding exactly how seizures stop, and whether CSD plays a protective or harmful role, is vital.

THE STUDY

This study will investigate how seizures naturally stop, with a focus on cortical spreading depressions following a recently discovered new way to trigger them in the lab and examine how they arise. Using their new experimental model, the team will closely examine what happens inside neurons during and after seizures. They aim to identify the molecular triggers caused by CSD and how this process might both stop seizures and, in some cases, cause harm. This work may also lead to the development of new medicines that can safely stop seizures and reduce the risk of SUDEP.

SIGNIFICANCE

This research tackles one of the biggest unanswered questions in epilepsy: how seizures end naturally. Some outcomes researchers hope for are new drug targets, new tools to test epilepsy treatments and a computer model to simulate seizure activity. This work could be transformational in the long-term if it reveals new treatment strategies that work with the brain's natural defences to better control seizures and reduce the risk of SUDEP.

RESEARCH AWARDS 2025



Finding the silent causes of seizure risk

GRANT TYPE: Emerging Leader Fellowship
GRANT AMOUNT: £300,000
LEAD INVESTIGATOR: Dr Robert Graham
CO-INVESTIGATOR: Professor Dimitri Kullmann
INSTITUTION: UCL Queen Square Institute of Neurology

BACKGROUND

For many people with epilepsy, not knowing when a seizure will happen is difficult. Many people describe "seizure clusters" or periods where seizures seem more likely, however the reasons for this are unclear. EEG recordings don't show strong warning signs before seizures, suggesting that deeper, slower changes in the brain may be involved. One possible factor is a chemical messenger in the brain called acetylcholine (ACh), which helps regulate brain activity but has been hard to measure over long periods.

THE STUDY

This study will use new fluorescent tools that can track ACh levels in real-time, across multiple days. The aim is to find out whether changes in ACh levels can explain when and why seizures start. The study will first record ACh activity in healthy animals, then in animals with epilepsy, and finally test how manipulating ACh affects seizure timing and spread.

SIGNIFICANCE

By uncovering how brain chemistry changes before and during seizures, this research aims to explain why seizure risk goes up and down – something that could eventually help forecast seizures. The study will provide crucial insights into what makes the brain vulnerable to seizures and could lead to new drug targets.



Investigating how calcium channel dysfunction causes epilepsy

GRANT TYPE: Emerging Leader Fellowship
GRANT AMOUNT: £299,998.77
LEAD INVESTIGATOR: Dr Marisol Sampedro Castañeda
CO-INVESTIGATORS: Dr Roope Mannikko, Professor Dimitri Kullmann
INSTITUTION: UCL Queen Square Institute of Neurology

BACKGROUND

Developmental and epileptic encephalopathies (DEE) are rare but severe childhood epilepsies caused by genetic mutations. Two types – DEE69 and DEE2 - are caused by mutations in different genes, but both appear to disrupt the same protein in the brain called Cav2.3. This protein is essential for regulating brain activity, brain development, and preventing seizures.

THE STUDY

This study will explore how Cav2.3 contributes to epilepsy by looking at different mutations. First, the team will test how mutations in Cav2.3 affect calcium flow and link these changes to symptoms and treatment responses. Next, they will investigate Cav2.3's role in early brain development, to find out when treatments might be most effective. Finally, they will test if Cav2.3 overactivity causes seizures in DEE2. These experiments will help to explain how Cav2.3 contributes to epilepsy and whether targeting it could lead to new, more personalised treatments.

SIGNIFICANCE

This research could explain how changes in Cav2.3 lead to seizures and help identify the best way to treat them. It may lead to more tailored therapies for children, reduce the number of medications needed and guide treatment decisions for affected families.



AI-based detection of Infantile Epileptic Spasms from infant movements in videos

GRANT TYPE: Endeavour Project Grant
GRANT AMOUNT: £174,981.70
LEAD INVESTIGATOR: Dr Edmond Shu Lim Ho
CO-INVESTIGATORS: Professor Sameer Zuberi, Professor Neil Patel
INSTITUTION: University of Glasgow

BACKGROUND

Infantile Epileptic Spasms (IES) are a serious and time-sensitive form of epilepsy that occurs in babies. Early and accurate diagnosis is essential for effective treatment and better long-term outcomes. However, recognising IES is difficult, even for specialists.

THE STUDY

This project will develop an AI-based system to detect signs of Infantile Epileptic Spasms from videos recorded on smartphones using the NHS-approved Create Health Web-App to securely collect video recordings. These videos will then be assessed and labelled by clinical experts to identify key body movement patterns linked to IES and then train an AI tool to automatically recognise the signs. The Shape Network will help co-design a tool that supports caregivers to capture high-quality, clinically useful videos.

The end goal is to integrate this AI system into a decision-support tool, which would aid, not replace, clinicians when diagnosing IES.

SIGNIFICANCE

This research has the potential to transform the way IES are detected. Accurate analysis of everyday smartphone videos could shorten the time to diagnosis and improve access to expert evaluation. If successful, this system could reduce pressure on healthcare services, enhance early intervention, and improve the quality of life for infants with epilepsy and their families.



Can a small biosensor attached to the chest by an ECG patch detect breathing patterns, including stopping breathing, during and after epileptic seizures?

GRANT TYPE: Endeavour Project Grant
GRANT AMOUNT: £146,404.75
LEAD INVESTIGATOR: Professor Sameer Zuberi
CO-INVESTIGATORS: Dr Ross Langley, Professor Andreas Brunklaus, Professor Neil Patel
INSTITUTION: Royal Hospital for Children and University of Glasgow

BACKGROUND

People with epilepsy are at risk of stopping breathing during or shortly after a seizure. This can lead to a Sudden Unexpected Death in Epilepsy (SUDEP), one of the most devastating outcomes for people with epilepsy and their families. Identifying early signs of abnormal breathing could help prevent SUDEP, but tools to monitor breathing in real-world settings are lacking. Pneumowave is a small chest-worn sensor, originally developed to detect life-threatening breathing pauses in people who had overdosed. It has already been safely tested in children with neurodisability.

THE STUDY

This study will test Pneumowave's potential to detect changes in children undergoing inpatient epilepsy monitoring, as well as in people with Dravet Syndrome (a rare, severe form of epilepsy with a high SUDEP risk) within the home environment. The device will be used alongside other monitoring equipment and evaluated for accuracy, comfort, and ease of use.

SIGNIFICANCE

If successful, this sensor could lead to the development of a reliable seizure-related breathing alarm for use at home. This could help prevent SUDEP by alerting carers or family members to breathing problems in time to intervene. The findings will also improve our understanding of breathing patterns during seizures and guide future safety measures.

TWO NEW PUBLICATIONS SET OUT OUR VISION

This year, the Institute published two keys documents that illustrate our determination to radically transform epilepsy research and explain how we will achieve this.

Strategic Plan 2025-2030

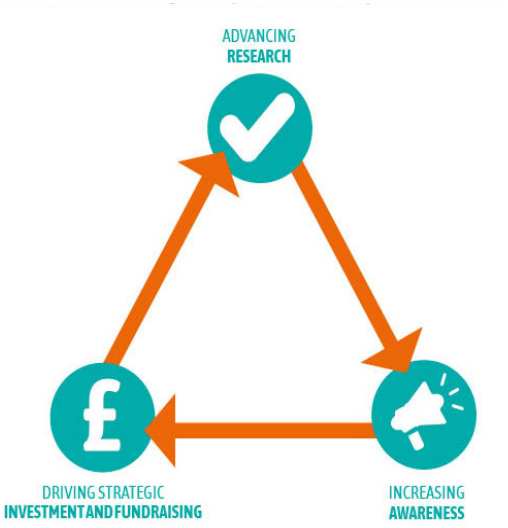


We published our Strategic Plan 2025-2030 "Transforming Lives" in Spring 2025. This 5- year Strategy sets out the decisive steps we will take to accelerate discovery, foster collaboration, drive investment, and translate research into positive outcomes for the one in 100 people living with epilepsy.

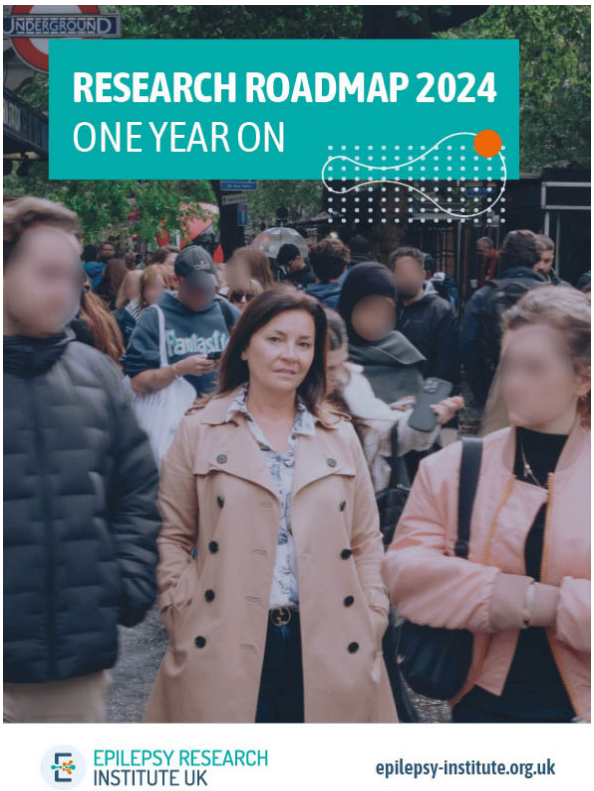
Grounded in the priorities identified by the epilepsy community through the robust James Lind Alliance priority-setting methodology, this strategy will significantly enhance our research capabilities, ensuring that outcomes are meaningful, accessible, and translatable into clinical practice. Our research model, built around the six key themes that we described in last year's annual report, is already guiding national and global efforts to transform the landscape of epilepsy research, and we plan to build on this strong foundation.

Key Strategic Goals

The implementation of this strategy will require a comprehensive and focused approach. As such, our plan is structured around our three strategic goals, which serve as the foundation for growth, impact and sustainability. These are illustrated in the diagram opposite.



Research Roadmap 2024



Underpinning our strategic ambition, is our Research Roadmap which was published in Autumn 2024 and is designed to unlock the transformative power of research and thereby enable us to make significant advances in our ability to diagnose, treat and prevent epilepsy.

The Roadmap describes how we are bringing together world class research communities and unlocking the knowledge barriers that have historically slowed progress in the sector.

Building on our progress to date and the longer-term ambition in each of our six themes we are confident we will achieve a systemic shift in research outcomes. Accelerating research in this way will enable people living with epilepsy to maximise their independence and live more fulfilled lives, which is central to the Institute's work.

We look forward to continuing to develop and strengthen our networks to maximise our impact. With us all working together in ever greater collaboration we will transform how society views epilepsy and energise the research efforts that will bring benefit to the one in 100 living with epilepsy and their families. Publishing this roadmap is a crucial step in that journey.

SHAPE NETWORK

The Epilepsy Research Institute's Shape Network is the UK's largest community of research-interested people affected by epilepsy. Through the network, we share opportunities to learn about the science of epilepsy, take part in studies, and shape research.

We now have over 690 people affected by epilepsy, based across the UK, in the Shape Network. It's fantastic to be connected to so many people who want to use their lived experience to advance research and improve the lives of people affected by the condition. In the coming year, we have plans in place to extend the invitation to join the SHAPE network to colleagues in Europe.

2024 – 2025 was a busy period for our Shape Network and some of the key activity is outlined below.

Application Clinics

Each year, during our rigorous Grant Round, members of the Shape Network give constructive feedback to the researchers applying to us for funding, through our Application Clinics. The shortlisted researchers start by presenting the background to their research area, the aims of their proposal, the potential impact, and outline the funding required. The Shape Network members and the researchers then have a lively discussion about how the research will benefit people affected by epilepsy, future clinical avenues for the research, how best to involve people with lived experience, and how to communicate in an accessible way.

In 2024, we ran 23 clinics from the end of November to the end of December.

Dr Francesca Chaloner, who was awarded the Institute's first Entry Fellowship in the 2024-25 Grant Round, shares her experience of the Application Clinics below.

"The ability to discuss my work with people living with epilepsy allows me to ensure my work is always delivered in the wider context of real-world impact for them. My future fellowship applications are already in line with the insights provided in my first Application Clinic meeting but will be improved upon with further discussions."

You can read more about our grant funding process and the awards made this year on page 20.

Epilepsy Research Institute as co-applicants

The Institute is also helping to leverage funding into epilepsy research by acting as a co-applicant when researchers are applying to other funders. The Epilepsy Research Institute supports these applications by delivering a bespoke programme of patient and public involvement and engagement (PPIE) activity, helping to ensure that the voice of people affected by epilepsy is central in these research projects.

EpiSafe Programme

In the UK, epilepsy affects 0.4% of women giving birth, but accounts for 10% of maternal deaths. The National Institute for Health and Care Research (NIHR) has invested over £2.7 million in research aiming to reduce maternal mortality risk and improve the care of pregnant women with epilepsy. The episafe programme is led by researchers at the University of Birmingham and Liverpool, in collaboration with the Epilepsy Research Institute's Shape Network.

Activity so far

An Advisory Group coordinated by the Epilepsy Research Institute, made up of women affected by epilepsy with experience of pregnancy, has been working closely with the researchers on all aspects of the EpiSafe programme. The group developed the questions for an interview guide, so that the team could get the best out of their interviews with women with epilepsy to understand their experiences of maternity care for the qualitative aspect of the study.

The Advisory Group have also shared their experiences of care during pregnancy to help inform the development of a tool designed for midwives to use when working with people with epilepsy. Now that the tool has been co-designed by researchers, healthcare professionals, and people affected by epilepsy, it will be trialled at sites across the UK to test if it improves maternal care.

EpiSafe is also studying the long-term neurodevelopment of children exposed to the newer anti-seizure medications while they were in the womb. The Advisory Group have been busy helping with participant information sheets and recruitment posters for this part of the study.

Using AI and data analysis to tackle drug-resistant epilepsy

The Medical Research Council awarded £1.1 million in funding to a new research collaboration between Swansea University and King's College London to improve outcomes for people living with drug-resistant epilepsy. This partnership brought together clinicians, data scientists and AI experts at the two universities, as well as individuals with lived experience from the Epilepsy Research Institute's Shape Network.

Around 30% of people with epilepsy do not respond to medications so, therefore, face increased risks from seizures, memory, and mood problems.

Using state-of-the-art natural language processing, artificial intelligence and routinely collected data this project will work to understand more about drug-resistant epilepsy. The team will use technology to study anonymised data that is already collected by healthcare professionals to improve and prioritise treatments.

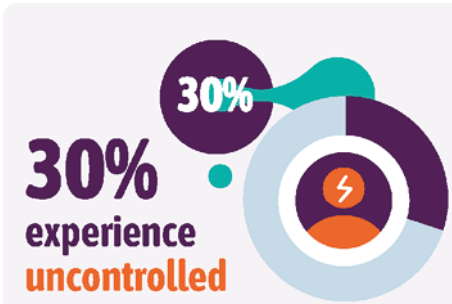
The two centres, King's and Swansea, have previously worked independently to develop state-of-the-art methods to extract relevant information from thousands of health records. Joining forces and working with the SHAPE network will allow them to accelerate progress. We are excited to provide support for this work which addresses several of the top ten priorities for epilepsy research in the UK.

The views from the Shape Network and the wider epilepsy community reinforce the importance of investing into research into epilepsy, especially when the impact on those living with the condition, and the effect on their immediate family members is better understood. However, the general public often has limited knowledge in this regard, which is why 'Increasing Awareness' is one of our key strategic objectives.

THE ONE IN 100 CAMPAIGN

In the UK, one in 100 people live with uncertainty, live with fear – live with epilepsy.

In Autumn 2024, The Epilepsy Research Institute launched its boldest and most ambitious campaign to radically change the numbers on epilepsy for good.







The campaign has three aims:

1. Raising awareness for the One in 100
2. Accelerating investment for the One in 100
3. Radically advancing research for the One in 100

With a new cohort of MPs recently elected, the Epilepsy Research Institute asked supporters to help us recruit a network of parliamentarians to champion the cause of epilepsy research. In the first few months, 405 MPs were contacted, 19 signed up as campaign champions and five written questions on epilepsy research were tabled in Parliament.

Our network of MP advocates will play a vital role in raising awareness, securing the necessary support for research and delivering better policies for people affected by epilepsy.

ONE IN 100 Facing fear, **finding hope**

One in 100 people live with epilepsy and each year:

There are **100,000** emergency hospital admissions

It costs the NHS **£2 billion**

Yet government spending per person on epilepsy research is much lower than other neurological diseases:

£21 for epilepsy

£97 for dementia

£234 for Parkinson's disease

It's time to change these numbers for good.

We will encourage them to support people affected by epilepsy and the work of the Institute by:

- Showing their support on social media.
- Tabling written and oral questions related to epilepsy research and funding.
- Referencing our briefings and reports in parliamentary debates to highlight key issues affecting those living with epilepsy.
- Applying for debates focused on epilepsy care, research, and treatment advancements.
- Championing stronger policies that improve research investment, and long-term outcomes for people with epilepsy.

MPs advocating for epilepsy research will help ensure that the voices of over 630,000 people living with epilepsy in the UK are heard in Parliament.

We sent out fundraising appeals to supporters to help us fund the next generation of research innovations through one-off donations or signing up to be a regular giver. All the money raised in the One in 100 campaign will drive and enable life changing research into epilepsy.

We also provided campaign resources for our thousands of supporters to help raise the profile of epilepsy research and encourage more people to join the movement for the One in 100.

One in 100 people live with epilepsy in the UK



THE PEOPLE BEHIND THE NUMBERS

At the heart of the One in 100 campaign are the real lives impacted by epilepsy. Here we meet four of these individuals, Sophie, Faye, Joy, and Murray, whose stories reflect the challenges and the hope of living with epilepsy.



Joy

My sister Jill was 21 when she realised something wasn't right. She was pregnant and had tightening's in her hands and jaw. Jill was diagnosed with epilepsy and several years later she began having nocturnal tonic clonic seizures that left her exhausted and often in pain for days, but unless you knew her story, you would never guess she had epilepsy, or any injuries sustained from a seizure.

I last saw Jill on a Friday evening laughing about life events. The very next night Jill had several seizures in succession. Sadly, she didn't regain consciousness; her heart just couldn't cope with the number of seizures. Jill was just 41.

I struggled deeply with my grief. A few years later, I realised I had to do something to help others. I want to raise funds for research as without this, how will there ever be a cure? My sister no longer has a voice, but I will be her voice. I will keep her name alive and do everything I can to prevent other families from enduring the loss we have.



Sophie

I was formally diagnosed with epilepsy in the summer of 2011, aged 11. I just wanted it to go away. I wanted answers about how to make it stop. I was willing to do anything. My learning was severely impaired, and my grades slipped a lot after I began to have seizures. I wanted to be a normal kid so badly, but it wasn't always possible.

Being part of Dr Valentin's research was truly life changing. Despite being one of the first patients on the trial, from the very beginning, me and my family felt we were in safe hands. Multiple surgeons had advised me that due to the location of brain tissue that would need to be removed and the invasive nature of the surgery, I would more than likely end up paralysed on the right-hand side of my body, but the entire team did their utmost to prove these odds wrong.

Thanks to this research, I was able to undergo successful brain surgery, with minimal side effects. I had my last seizure the morning of the surgery and have since been seizure-free for 10 years.



Murray

I've been living with epilepsy for 28 years. I first experienced absence seizures, which initially occurred six times a day, but have now reduced to five or six times a month. However, there was a time when I had a cluster of 90 seizures in a single weekend.

I rarely receive warning before a seizure, leaving me little time to prepare. This has led to slips, trips, and near accidents; almost walking off train platforms three times but thankfully stopped by kind strangers each time. The side effects include frequent headaches, fatigue, low mood, and forgetfulness.

A few years ago, my neurologist asked if I would be interested in participating in a trial for a new device called 'SubQ' designed to forecast seizures. The SubQ would monitor seizures, muscle movements, brain signals, and other metrics to help predict seizure occurrences.

The trial was successful and provided valuable insights. I'm not seizure-free, but I believe SubQ represents a significant step towards that goal. If it can prevent others from experiencing harm, that would be the most meaningful gift. I am already experiencing the impact of future epilepsy technologies first-hand. It feels important.



Faye

I have been a child with epilepsy and a young adult at university managing my epilepsy alone for the first time. I have travelled the world, and I have been a woman, a pregnant woman and now a mum with epilepsy. It has given me a unique insight into life with this condition. More than ever in recent years, the need to advocate for women with epilepsy has been at the forefront of my mind.

Epilepsy has knocked me down in so many ways. I understand the challenges facing young people, like balancing wanting to socialise versus the need to sleep and keep yourself well. Then having serious seizures as an adult and being hospitalised in pregnancy, and again while raising a baby and toddler. Dealing with the sleep deprivation, managing the anxiety of never knowing when you could have a seizure.

In an ideal world I hope we find a cure, a way to live seizure free. In the mid-term, I hope for a medication that doesn't cause side effects because I have spent many years of my life balancing the risk of seizure against living with the side effects of the medication. They can also be so debilitating.

OUR RESEARCH OUTCOMES

At the Institute we know that research saves and improves the lives of people living with epilepsy. The journey from funding the first research study through to seeing new diagnostics, treatments or care pathways rolled out in the NHS is often a long one. However, we can speed this up by working in partnership with academics, clinicians, industry, government bodies and most importantly people affected by epilepsy.

Tracking outcomes and impact starts with looking at final reports to see what each funded project has achieved and where the research will go next. This includes whether the projects are able to secure further funding; typically for every pound we invest in research, a further £5.41 is leveraged in follow on funding.

We also track peer-reviewed scientific papers. In the financial year 2024-2025, 40 new academic papers were published acknowledging our funding. This includes papers in the high impact journals Nature, The Lancet, Brain and JAMA Neurology. Each paper contributes new knowledge and understanding about the epilepsies to move the field forward towards breakthroughs.

Here we highlight three projects that finished this year, demonstrating some very different areas of research and how they all contribute to increasing understanding of the causes and mechanisms of the epilepsies and associated conditions. Through research like this, innovations in prevention and treatment are made possible. Investment in projects like these strengthens the epilepsy research ecosystem, and it's great to see partnerships and collaborations developing as a result.

Project Title: Volatile non-invasive biomarkers of epileptic seizures (VIBES)

Grant holders: Matthew Walker (Principal Investigator); **Co-applicants:** Eleonora Lugara, George Hanna, Ilaria Belluomo
Host Institutions: University College London, Imperial College London
Duration of project: 01/12/2021 - 30/11/2024

This study has demonstrated the potential for breath tests to distinguish between seizures caused by epilepsy and other causes. Currently, at least one in five people are misdiagnosed with epilepsy and, conversely, many people with epilepsy have significant delays before getting a diagnosis. A wrong diagnosis can lead to unnecessary or delayed treatments.

Levels of small molecules in people's breath can give a precise picture of what is happening in the body in that moment. They can be collected quickly, easily, and painlessly, even in an emergency.

By collecting breath samples before and after seizures in a group of 133 people, the VIBES research study looked at which molecules were altered in their breath. The study found that some molecules increase or decrease only in one seizure type , showing some potential to help tell the difference between epileptic and non-epileptic seizures.

To develop a reliable diagnostic test, the findings need to be confirmed in a larger group of patients. Dr Ilaria Belluomo was awarded an Emerging Leader Fellowship in 2024 to continue this exciting work as well as investigating if molecules in the breath and on the skin could be used to predict seizures.

Project Title: Identifying SUDEP risk: sleep-wakefulness modulation of central autonomic and respiratory networks

Grant holders: Beate Diehl (Principal Investigator), **Co-applicant:** Louis Lemieux
Host Institution: University College London
Duration of project: 03/08/2020 - 30/12/2024

SUDEP (sudden unexpected death in epilepsy) often occurs at night, so this study researched how the heart, breathing and brain connections differ in people with epilepsy, and investigated how sleep may influence this.

A new method was created and tested to see how connections between brain areas involved in breathing and the cardiovascular system are different in people with epilepsy, including people who later died of SUDEP. MRI scans looking at brain connectivity were performed at the same time as EEG and ECG which measure brain activity and heart rhythms. Preliminary analyses based on 90 scans from UCL led to some important observations. During sleep, people with epilepsy have connectivity changes in key brain areas: the amygdala, which is important for breathing control, the insula, an important site to modulate heart rate, and an area called BA 25, which helps maintain steady blood pressure. The next steps are to perform these analyses on over 240 scans already collected from people with epilepsy at several international centres to see how these connectivity changes are related to the risk of SUDEP.

Project Title: The SAIL Epilepsy Research Cohort (SERC) - A scalable resource leveraging anonymised population data and natural language processing for epilepsy research, pilot study.

Grant holders: Owen Pickrell (Principal Investigator); **Co-applicants:** Lyons RA; Lacey AS; Vuksanovic V; Akbari A; Powell R; Sawhney IMS; Smith PE; Hamandi K; Anderson J; Johnston A
Host Institution: Swansea University
Duration of project: 01/12/2022 - 30/11/2023

This project developed a computer system called ExECT (Extraction of Epilepsy Clinical Text), which uses natural language processing (NLP) to automatically read clinic letters and extract key information. This information allowed researchers to learn more about refractory epilepsy, where people continue to have seizures despite treatment with two or more epilepsy medications.

The research used routinely collected NHS data—covering everyone who receives care - and including the important details about a person's epilepsy (such as seizure frequency or type) in clinic letters, written in different ways by different doctors. The project applied ExECT to 280,000 neurology clinic letters finding over 8,000 people with epilepsy, covering 10 years. There is now a detailed and anonymised research dataset called the SAIL Epilepsy Research Cohort (SERC) available for other researchers to develop and use.

18% of people in this group were found to have refractory epilepsy. Surprisingly, only a third had the terms "drug-resistant" or "refractory" epilepsy mentioned specifically in their clinic letter, so information about their seizure frequency and the medications that they had tried was used to identify the others.

This grant has allowed the researchers to leverage £1.1million in new funding, to expand this work nationally. They'll use AI to predict who might develop refractory epilepsy—so we can intervene earlier and improve care for those who need it most. The Institute's Shape Network are collaborating on this new study to ensure that the outcomes are focussed on what is most important to those with refractory epilepsy.


Army Parachute Association

OUR AMAZING SUPPORTERS

An amazing 327 people took part in sporting challenges this year to raise vital funds for us to use to radically advance research into epilepsy. We would like to say a massive thank you to each and every one of them and wish we could include the stories of all these incredible people.

In total, £283,451.14 was raised through the efforts of these super supporters. Over the page are just a few examples of the things they did:

SUPPORTER EVENTS

London Marathon

April 2024

11 runners took part on the hot sunny day in April. We had a great group of runners who raised a staggering £41K (more than double 2023).

April 2025

We had a smaller team of eight committed runners, half of whom joined us with their own place. Together, the brilliant team raised £26K which was £13K over the minimum target.

A member of our team running in memory of his daughter was captured crossing the line in an emotional video. This was put on TikTok and gained four million views, which was great for increasing awareness of both the Epilepsy Research Institute and the cause in general.



Left: Lizzie Smith after running the London Marathon 2024



Right: Andrew Rosewell after running the London Marathon 2025

Madrid Marathon - April 2025

In Madrid, a supporter named Gracie took part in the marathon. Since signing up, she tragically lost her sister to epilepsy. Fuelled by this heartbreak, she and her fellow runners raised a staggering £78,000 – a truly remarkable achievement that honours her sister's memory.



Above: Gracie after finishing the Madrid Marathon 2025

Below: Gracie Cameron with friends and family in Madrid





Right: Julia Pyke at the Skydive 2025



Left: Linda, Nigel and Anya after taking on the Skydive

Skydive - May 2025

Over the month, nine participants enjoyed a great day across three 'dropzones'. For a first event for us, it was a great success and raised £10K, so we plan to repeat it every year. Jumping out of a plane is often seen as one of the ultimate ways to show commitment to the cause, so a huge thank you to those who took on this challenge and please do join us next year!

"My son has epilepsy, as do some of our family members and friends, so it's a really really important cause that we want to raise money for." – Julia Pyke

Farnell Golf Day 2024

Farnell's annual golf day has become a cherished tradition, not just because it raises a fantastic £10,000 per year, but to honour the memory of John Hirst's son, James. The employees and supplier teams who take part are proud to support such meaningful, life-changing work.



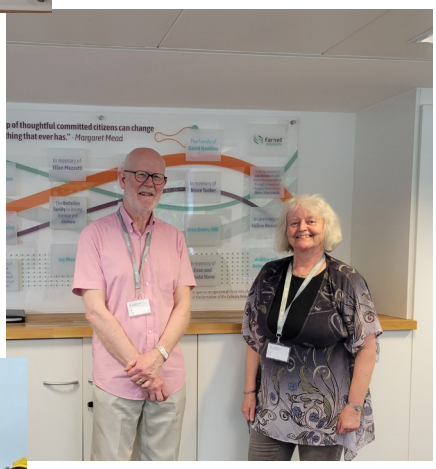
Above: Our CEO Rosemarie Pardington at the Farnell Golf Day in 2024



Left: The Founders Wall at Epilepsy Research Institute Head Office

Founders' Wall

The official unveiling of our founding funders' wall this year was another small way to acknowledge just how much their contribution is appreciated and the positive impact this has made.

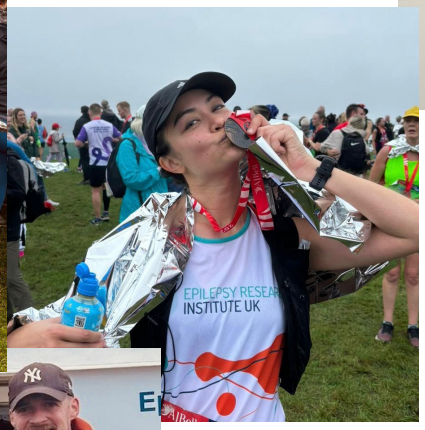


Above: Simon and Lucy Harding at the unveiling of the Founders' Wall

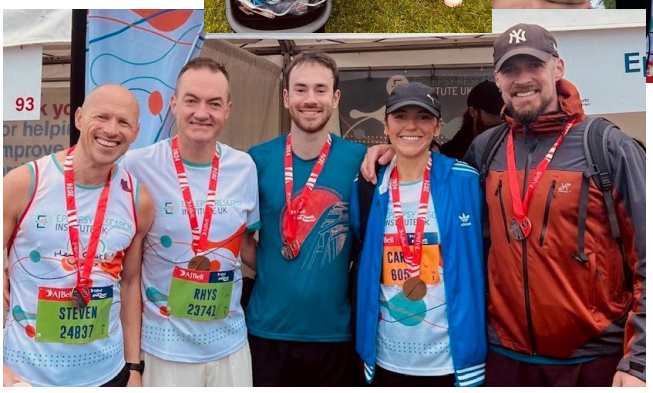
Right: David Bowmaker with his family after the run



Below: Ariel Chelsey after running the Great North Run 2024



Below: Steve, Rhys, Tom, Carly and Dan with their medals



Great North Run - September 2024

We had 38 runners on the day including Institute Trustee, Dr Rhys Thomas, and other researchers from Newcastle. The event raised £29K which was an £11K increase on 2023.

1,000 Mile Bike Ride

Martin Verspeak was inspired to do this after his granddaughter was diagnosed with epilepsy. He said:

> "I honestly thought it wasn't something I could do physically. I can look back with a huge sense of pride. I'd like to see improvements in medication so we can move the number of people being successfully treated from around 65% to as near 100% as possible."

Below: Martin Verspeak with granddaughter Eliza and family



TRUSTEES' REPORT AND FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

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 31 March 2025.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the 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 2019).

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 PhD FRCP (Chair)
Mr Barrie Akin LLB FCA
Professor Michael Cousin BSc PhD
Dr Anne Coxon DPsych (Resigned March 2025)
Mr Mark Devlin BSc MSc
Professor Martin Elliot MB BS MD FRCS
Dr Abbie Fearon-Yorke PhD
Professor Nicholas Lench BSc PhD FRCPath
Mr Simon Lodge MA FIA (Appointed December 2024)
Professor Tony Marson MB ChB MD, FRCP FEAN
Professor Mark Richardson MA BMBCh MRCP PhD CCST FRCP
Ms Rebekah Smith BA (Hons) DipM ACIM CMgr FCMI
Ms Juliet Solomon
Miss Judith Spencer-Gregson MSc FCA
Dr Rhys Thomas BSc MSc PhD MBChB MRCP
Dr Sukhvir Wright BSc PhD MBBS
Mrs Lesslie Young OBE

President
Professor J Helen Cross OBE MB ChB PhD FRCP(UK) FRCPCH

Chief Executive
Ms Rosemarie Pardington BSc (Hons) MBA Ad DipPR DipM DipSS MCIM MIQA

Independent auditors
Kreston Reeves, Springfield House, Springfield Road, Horsham, West Sussex, RH12 2RG

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
Bevan Brittan LLP, Kings Orchard, 1 Queen Street, Bristol BS2 0HQ
Broadfield Law UK LLP, One Bartholomew Close, London EC1A 7BL (Previously known as BDB Pitmans LLP)

Registered Charity number 1100394
Registered Company number 4873718

Head Office
Churchill House
35 Red Lion Square
London WC1R 4SG

OBJECTIVES AND ACTIVITIES FOR THE PUBLIC BENEFIT

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.

Financial Review

In 2024-25 overall incoming resources were £1,700,383 (2024: £3,595,109) as we did not receive funding from grants as in the previous year (2024: 1,478,851).
The costs of raising funds were £269,065 (2024: £177,658) as we strengthened our team in order to achieve the targets set in our new five-year strategy.
We were able to maintain a similar level of expenditure on charitable activities of £2,585,987 (2024: £2,913,605) and plans for 2025-26 will further increase this figure.
It was always recognised that in the first two years establishing the Institute would see significant initial investment in the resourcing of the organisation.

Despite not receiving a government grant this year, we were able to award grants of £1,715,228 during the year (2024: £2,028,835) despite the reduction in income, giving a total amount of grants committed to £5,937,436 (2024: £6,314,802.

Bank balances of £678,631 (2024: £2,197,361) are held for ongoing grant commitments and day to day liabilities, with a further £3,883,191 (2024: 3,430,622) held in a liquidity fund with our investment managers to access if necessary.

Specific investment powers of the Trustees

The Trustees, having regard to the liquidity requirements of research grants awarded, have invested funds in medium and long term investments and also hold an amount of treasury cash. Income from investments performed well and there was a net investment gain of £44,269 (2024: Loss of £278,842).

Going Concern

The Trustees regularly check the Balance Sheet value and consider the implications of grants that are funded each year. The net result for 2024-25 was significantly lower than in previous years, but careful consideration of our reserves allowed us to award a similar level of grants as in previous years, proving that the reserves policy was robust.
The balance sheet shows reserves of £3,067,872 (2024: £4,178,272) and the Trustees are confident that we will be able to meet our commitments and consider the charity to be a going concern.

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 based on the financial impact of the current risks facing the charity and is formally reviewed each year 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.

Designated reserves are held to enable the charity to focus on awarding a sustainable level of research grants supporting the strategic priorities of the charity. The Trustees consider that in order to meet these needs, and to operate effectively, the charity needs reserves of around £1,210,000 (2024: £900,000). Designated research funds at 31 March 2025 are £1,857,872 (2024: £3,278,272) which will enable the charity to focus on a sustainable level of research grants supporting the refreshed strategy.

Fundraising approach and performance in 2024-25

The overall incoming resources from donations and legacies during 2024-25 were £1,324,802 (2024: £1,886,154) a decrease in income of 30% compared to the previous year. This was due to a substantial decrease in legacy income during the year - £260,306 compared to £997,334 in 2023-24. Income from legacies is always difficult to predict, and the total number notified during the year was similar to previous years. However, it is likely that legacy income will revert to the usual levels in 2025-26. We are always humbled by the generosity of those who remember us in their Wills.

Last year, 65% (2024: 24%) of our donations (excluding legacies) came from our community of supporters. 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 of the continuing cost-of-living crisis on our supporters and will ensure 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. 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.

Looking ahead, we are placing greater strategic focus on fundraising to ensure we can deliver our organisational aims in line with our new strategy. We have engaged a specialist fundraising consultant to help review and strengthen our approach, and their recommendations are guiding a refreshed direction. This includes developing a more sustainable income mix, investing in supporter engagement, and adapting our internal structures. As part of this, we are making some changes within the team to ensure we have the right skills and capacity in place to support long-term growth and resilience in our fundraising efforts.

Structure, governance and management

Governing document

The Epilepsy Research Institute UK is a charitable company limited by guarantee, incorporated (as Epilepsy Research Foundation) on 21 August 2003 and registered as a charity on 30 October 2003. The company is governed by its Articles of Association.

On 22 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 30 March 2007.

On 8 June 2023, the name of the organisation was amended from Epilepsy Research UK to Epilepsy Research Institute following a special resolution passed on 15 May 2023.

On 1 October 2024, new Articles of Association adopted by a special resolution presented to Trustees and Members at the Annual General Meeting of the charity.

Members of the charity include the original signatories of the Memorandum and Articles of Association, current and past Trustees as well as those specifically asked to act as Members. Every Member promises, if the charity is dissolved while they are a Member or within 12 months afterwards, to pay up to £1 towards the costs of dissolution and the liabilities incurred by the charity while they were a Member.

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 Institute UK as sole member. Confirmation statements and dormant company accounts are submitted for these two entities to Companies House on an annual basis.

Organisation

The activities of Epilepsy Research Institute UK are governed by the Board of Trustees, all of whom are Directors. The Board meets four times per year. There are three key subcommittees; the Nominations and Advisory Subcommittee and the Finance & Audit Subcommittee and the Scientific Advisory Committee.

The Chief Executive is appointed by the Trustees to manage the day-to-day operations of the charity.

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 on a voluntary basis.

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 seven and a maximum of sixteen Trustees, with the option to extend beyond this by ordinary resolution.

Under the new Articles of Association, Trustees are able to serve for a fixed three-year term of office, renewable once to a maximum of a six -year term. The exception to this is where a Trustee may have opted for a shorter term on election.

As part of the adoption process of the new Articles to ensure continuity and to allow for succession planning, Trustees were appointed on a variety of terms from one to three years.

Founding Partner Trustees

Crucial to the establishment of the Institute, a number of Founding Partner organisations were put at the heart of its strategic development to ensure the whole epilepsy community could drive the collective research agenda. This

included:

- Epilepsy Action
- Epilepsy Scotland
- International League Against Epilepsy (British Branch)
- Young Epilepsy

Ahead of the adoption of the new Articles of Association, the relationship with Founding Partners was directed by a specific Memorandum of Understanding (MoU). However, the new Articles brought an opportunity to enshrine the role of Founding Partners into the main Articles of the charity, and this has now superseded the MoU.

Key Strategic Partner Trustees

The new articles also made provision for the election of further Trustees/members to reflect future key strategic partnerships for organisations working alongside the Institute to further our objects. These organisations would have the same rights and powers as the Founding Partners.

There were no such elections during 2024-25.

Trustee induction and training

All new Trustees receive a copy of the Charity Commission publication 'The Essential Trustee'. We have provided a bespoke induction for the new Trustee appointed in December 2024, and he continues to access external training and educational events relevant to his new Trustee role and in particular for the finance aspects of his appointment.

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 11 to the accounts. The Board of Trustees, 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 usually reviewed annually by the Nominations and Advisory Subcommittee.

Risk management and disclosure

The Trustees consider strategic risk management to be an essential element in supporting the effective planning and evaluation of the Institute's activities. Risk management was focused on identified risks embedded in our strategic and operational processes. The 2024-25 risk register was approved at the Board of Trustees meeting in July 2024.

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. Master Operational Plan and budget which has regular Board of Trustees oversight
2. Financial controls and policies (such as reserves, investment policies and fundraising)
3.. Strategic partnership work.

Key areas of identified risk for 2024-25 were those associated with:

- Cyber security – which a number of control measures have been implemented across the year.
- Organisational policies and procedures – which has been addressed during the year through a comprehensive programme of development of policies and procedures. This included the Trustees signing off a new policy on delegated levels of authority.

In terms of our current risk profile, the Corporate Risk register was approved by the Board on 3 July 2025. Of particular note around the potential failure of not meeting all the ambitious financial targets.

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 regular basis.

Statement of Trustees' responsibilities

The charity Trustees (who are also the directors of Epilepsy Research Institute 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

Signed on behalf of the Board of Trustees on 25 September 2025

FINANCIAL STATEMENTS

Opinion on financial statements

We have audited the financial statements of the Epilepsy Research Institute UK ("the charitable company") for the year ended 31 March 2025 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement including changes in net debt and notes to the financial statements, including a 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).

In our opinion the financial statements:

- Give a true and fair view of the state of the charitable company's affairs as at 31 March 2025, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- Have been prepared in accordance with the requirements of the Companies Act 2006.

Basis 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 charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

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

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

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

Other information

The other information comprises the information included in the Trustees' Annual Report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the Annual Report. 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. 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 course of 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 this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

- The information given in the Trustees' Annual Report (incorporating the Strategic Report and the Directors' Report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- The Strategic Report and the Directors' Report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Strategic Report included within the Trustees' report.

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

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of directors' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

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

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conduct in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatement 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.

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

Capability of the audit in detecting irregularities, including fraud

Based on our understanding of the charity, and through discussion with the directors and other management (as required by auditing standards), we identified that the principal risks of non-compliance with laws and regulations related to GDPR and employment law. We considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006. We communicated identified laws and regulations throughout our team and remained alert to any indications of non-compliance throughout the audit. We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to posting inappropriate journal entries to increase revenue or reduce expenditure, the recognition of grants payable and revenue recognition.

Audit procedures performed by the engagement team included:

- Discussions with management and assessment of known or suspected instances of non-compliance with laws and regulations and fraud, and review of the reports made by management; and
- Assessment of identified fraud risk factors; and
- Holding discussions with appropriate personnel to gain further insight into the control systems implemented, and the risk of irregularity; and
- Performing analytical procedures to identify any unusual or unexpected relationships, including related party transactions, that may indicate risks of material misstatement due to fraud; and
- Confirmation of related parties with management, and review of transactions throughout the period to identify any previously undisclosed transactions with related parties outside the normal course of business; and
- Reading minutes of meetings of those charged with governance and reviewing correspondence with relevant tax and regulatory authorities; and
- Verifying the year-end cash at bank balances to online banking portals to verify accuracy; and
- Review of significant and unusual transactions and evaluation of the underlying financial rationale supporting the transactions; and
- Identifying and testing journal entries, in particular any manual entries made at the year end for financial statement preparation.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment 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 charitable company's internal control.
- • Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees
- Conclude on the appropriateness of the Trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation (ie. gives a true and fair view)

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

Use of our report

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

James Peach BSc FCA (Senior Statutory Auditor)
For and on behalf of Kreston Reeves LLP
Chartered Accountants and Statutory Auditor
Horsham
Date:

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2025

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £	Total Funds 2024 £
Income from:					
Donations and legacies	2	935,504	389,298	**1,324,802**	1,886,154
Grants	3	-	-	**-**	1,478,851
Other trading activities	4	11,110	-	**11,110**	3,608
Investments	5	364,471	-	**364,471**	226,496
Total Income		1,311,085	389,298	**1,700,383**	3,595,109
Expenditure on:					
Cost of raising funds					
Raising Funds	6	269,065	-	269,065	177,658
Charitable activities					
Research grants committed	7	1,279,625	199,914	**1,479,539**	1,999,070
Other research activities	8	1,084,328	22,120	**1,106,448**	914,535
Total charitable expenditure		2,363,953	222,034	**2,585,987**	2,913,605
Total expenditure		2,633,018	222,034	**2,855,052**	3,091,263
Net unrealised gains / (losses) on investments	12	44,269	-	**44,269**	(278,842)
Net income/(expenditure) for the year		(1,277,664)	167,264	**(1,110,400)**	782,688
Transfers between funds	16	167,264	(167,264)	-	-
Net movement in funds for the year		**(1,110,400)**	**-**	**(1,110,400)**	**782,688**
Reconciliation of funds:					
Total funds brought forward on 1 April		4,178,272	-	**4,178,272**	3,395,584
Total funds carried forward at 31 March	17	**3,067,872**	**-**	**3,067,872**	4,178,272

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 55 to 65 form part of these financial statements.

BALANCE SHEET
AS AT 31 MARCH 2025

	Note	2025 £	2024 £
Fixed assets			
Investments	12	**7,608,127**	7,552,532
		7,608,127	7,552,532
Current assets			
Debtors	13	**928,649**	846,091
Cash at bank and in hand		**678,631**	2,197,361
		1,607,280	3,043,452
Creditors: amounts falling due within one year	14	**(3,088,750)**	(3,417,158)
Net current (liabilities)/assets		**(1,481,470)**	(373,706)
Total assets less current liabilities		**6,126,657**	7,178,826
Creditors: amounts falling due within one year	14	**(3,058,785)**	(3,000,554)
Total net assets		**3,067,872**	4,178,272
The funds of the charity			
Unrestricted funds	15		
Designated funds		**1,857,872**	3,278,272
General fund		**1,210,000**	900,000
		3,067,872	4,178,272
Restricted funds	16	**-**	-
Total charity funds		**3,067,872**	**4,178,272**

The financial statements were approved by the Board of Trustees on 25 September 2025 and signed on its behalf by:

Prof Matthew Walker
Chair

Judith Spencer-Gregson FCA
Treasurer

Registered company number: 4873718
Registered charity number: 1100394

The notes on pages 54 to 65 form part of these financial statements.

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2025

	2025 £	2024 £
Cash (outflow)/inflow from operating activities	**(1,871,875)**	1,946,632
Cash flows from investing activities		
Sale of investments	**550,048**	-
Net purchase of investments	**(250,000)**	-
Income reinvested	**(311,374)**	(157,845)
Dividends and interest received	**364,471**	226,493
Net cash inflow/(outflow) from investing activities	**353,145**	(3,306,352)
Increase/(decrease) in cash and cash equivalents in the year	**1,518,730**	(1,359,720)
Cash and cash equivalents at the beginning of the year	**2,197,361**	3,557,081
Cash and cash equivalents at the end of the year	**678, 631**	2,197,361

Reconciliation of net movement in funds to net cash flow from operating activities

Net movement in funds	**(1,110,400)**	782,688
Deduct investment income shown in investing activities	**(364,471)**	(226,496)
Deduct investment gain/add (loss)	**(44,269)**	(278,842)
(Increase)/decrease in debtors	**(82,558)**	1,021,978
Increase/ (decrease) in creditors due within one year	**(328,408)**	490,590
Increase/(decrease) in creditors due after more than one year	**58,231**	156,714
Net cash from/used in operating activities	**(1,871,875)**	**1,946,632**

Analysis of cash and cash equivalents

Cash deposits	**1,886,696**	1,886,696
Cash at bank	**310,665**	310,665
Net Cash from/used in operating activities	**2,197,361**	**2,197,361**

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

Analysis of changes in net debt	**As at 31 Mar 24**	**Cashflows**	**As at 31 Mar 25**
Cash deposits and cash at bank	**2,197,361**	**1,518,730**	**678,631**

There were no overdrafts, loans or finance lease obligations within the period

NOTES FORMING PART OF THE FINANCIAL STATEMENTS FOR THE YEAR ENDING 31 MARCH 2025

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 (FRS102) (effective 1 January 2019) - 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 Institute UK meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant policy note(s).

Reconciliation with previously General Accepted Accounting Practice: in preparing the accounts, the Trustees have considered whether in applying the accounting policies required by FRS102 and the Charities SORP FRS 102 the restatement of comparative items was

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

Income is included in the Statement of Financial Activities when the charity has entitlement to the funds, certainty of receipt and the amount can be measured with sufficient reliability. 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 on the basis of 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.

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 ones extending over a year or more. All current grants are of a maximum duration of 4 years, and all grants are covered by our cash balances, deposits and investments.

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.

f) Interest receivable
Interest on funds held on deposit included when receivable and the amount can be measured reliably.

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) 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.

k) 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.

l) Leases
The charity entered in to a new operating lease in September 2023. Payments made under the lease agreement have been taken to expenditure.
The balance of the remaining lease is not shown on the balance sheet but is shown in note 19.

2 DONATIONS AND LEGACIES

	Unrestricted Funds £	Restricted Funds £	Total 2025 £	Total 2024 £
Charitable trusts	91,020	82,282	173,302	106,664
In memoriam donations	33,130	-	33,130	81,591
Other donations	277,919	307,016	584,935	365,590
Fundraising events	273,129	-	273,129	334,975
Legacies	260,306	-	260,306	997,334
	935,504	389,298	1,324,802	1,886,154

Donations and Legacies 2024

	Unrestricted Funds £	Restricted Funds £	Total 2023 £
Charitable trusts	36,664	70,000	106,664
In memoriam donations	81,591	-	81,591
Other donations	365,440	150	365,590
Fundraising events	334,975	-	334,975
Legacies	997,334	-	997,334
	1,816,004	70,150	1,886,154

Income from fundraising events arises from events organised by the charity and its supporters.
Online advertising to the value of £66,454 (2024: £66,393) 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.

3 GRANTS RECEIVED

	Unrestricted Funds £	Restricted Funds £	Total 2025 £	Unrestricted Total 2024 £
UKRI - Medical Research Charity Support	-	-	-	1,478,851

4 OTHER TRADING ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	Total 2025 £	Unrestricted Total 2024 £
Sale of christmas cards	11,110	-	11,110	3,608
Fees charged	-	-	-	-
	11,110	-	11,110	3,608

5 INVESTMENT INCOME

	Unrestricted Funds £	Restricted Funds £	Total 2025 £	Unrestricted Total 2024 £
Dividend & investment income	348,992	-	348,992	120,389
Interest on deposits	15,479	-	15,479	106,107
	364,471	-	364,471	226,496

6 COSTS OF RAISING FUNDS

	Unrestricted Funds £	Restricted Funds £	Total 2025 £	Unrestricted Total 2024 £
Direct fundraising	106,979	-	106,979	55,962
Staff costs	108,599	-	108,599	81,356
Other overhead expenses	25,351	-	25,351	24,992
Governance costs	28,136	-	28,136	15,348
	269,065	-	269,065	177,658

7 RESEARCH GRANTS COMMITTED

	2025 £	2024 £
Committed as at 31 March 2024	6,314,802	5,609,511
Authorised during year (see Trustees' report)	1,715,228	2,028,835
No longer required	(235,689)	(29,765)
Paid in year	(1,856,905)	(1,293,779)
Committed as at 31 March 2025	5,937,436	6,314,802

Authorised grants represent awards made to research institutions to further the understanding and treatment of epilepsy. An overview of the awards are set out in the Trustees report on pages 20-25. Details of all grants awarded are available on the website: epilepsy-institute.org.uk/eri/research/research-portfolio/. Grants no longer required relates to projects that were completed without the original grant being spent.

8 OTHER RESEARCH ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	Total 2025 £	Total 2024 £
Staff costs	597,454	8,474	605,928	488,993
Director of National Epilepsy	21,400	-	21,400	32,795
Research meetings, events & activities	84,179	13,646	97,825	54,654
Research awards & prizes	574	-	574	500
Research dissemination & communication	102,722	-	102,722	99,435
Institute transition	8,703	-	8,703	28,365
Overhead expenses	141,382	-	141,382	129,994
Governance costs	127,914	-	127,914	79,799
	1,084,328	43,753	1,106,448	914,535

Other Research Activities 2024

	Unrestricted Funds £	Restricted Funds £	Total 2023 £
Staff costs	449,704	39,289	488,993
Director of National Epilepsy	32,795	-	32,795
Research meetings, events & activities	50,992	3,662	54,654
Research awards & prizes	-	500	500
Research dissemination & communication	99,435	-	99,435
Institute transition	28,365	-	28,365
Overhead expenses	129,692	302	129,994
	79,799	-	79,799
	705,613	43,753	914,535

9 SUPPORT AND GOVERNANCE COSTS

	Support Costs £	Governance Costs £	Total 2025 £	Total 2024 £
Staff costs	-	63,170	63,170	31,336
Other staff costs	47,184	4,170	51,354	39,388
Office rent & facilities	61,875	5,468	67,343	49,675
Office running costs	11,159	986	12,145	29,676
IT & bank charges	46,515	4,111	50,626	36,247
Investment fees	-	35,808	35,808	25,623
Audit	-	17,390	17,390	16,200
Trustee meetings & expenses	-	12,103	12,103	12,325
Legal & professional fees	-	12,844	12,844	9,663
	166,733	156,050	322,783	250,133
Basis of allocation				
Allocated to fundraising costs	25,351	28,136	53,487	16.57%
Allocated to charitable activities	141,382	127,914	269,296	83,43%
	166,733	156,050	322,783	100.00%

Support and Governance costs 2024

	Support Costs £	Governance Costs £	Total 2024 £
Staff costs	-	31,336	31,336
Other staff costs	39,388	-	39,388
Office rent and facilities	49,675	-	49,675
Office running costs	29,676	-	29,676
IT and bank charges	36,247	-	36,247
Investment fees	-	25,623	25,623
Audit	-	16,200	16,200
Trustee meetings & expenses	-	12,325	12,325
Legal & professional fees	-	9,663	9,663
	154,986	95,147	250,133

	Support Costs £	Governance Costs £	Total 2024 £
Basis of allocation			
Allocated to fundraising costs	24,992	15,348	40,340
Allocated to charitable activities	129,994	79,799	209,793
	154,986	95,147	250,133

10 TOTAL AUDITOR'S REMUNERATION

	2025 £	2024 £
Remuneration in relation to the audit of the financial statements	17,390	16,200
Remuneration for other services: payroll processing	1,440	444

11 STAFF COSTS

	2025 £	2024 £
Salaries	677,382	524,683
Social security costs	70,897	53,180
Pension costs	29,417	23,822
	777,696	601,685

Employees receiving salaries within the following bands:

	2025	2024
£80,001 to £90,000		1
£120,001 to £130,000	1	

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

	2025	2024
Charitable activities	11	8
Fundraising	2	1
Governance	1	1
	14	10

Epilepsy Research Institute UK incurred total key management personnel remuneration costs during the period of £143,056 (2024: £122,426). The Trustees do not receive any remuneration for their duties and during the year received expenses of £6,231 for travelling to meetings (2024: £6,311). No Trustee or persons with family or business connections with Trustees has received remuneration directly or indirectly from the charity.

The charity includes Trustees' Liability Insurance in its combined insurance policy.

12 INVESTMENTS

	2025 Liquidity Fund £	2025 Long & Medium Term Portfolio £	2025 TOTAL £	2024 Long & Medium Term Portfolio £
Market value 1 April 2024	3,430,622	4,121,910	7,552,532	3,740,842
Acquisitions	250,000		250,000	3,375,000
Sales at market value	5,010	(555,058)	(550,048)	-
Investment charges	(7,335)	(1,325)	(8,660)	(18,473)
Income reinvested	204,894	115,140	320,034	176,318
	3,883,191	3,680,667	7,563,858	7,273,687
Net gain/(loss) realised		(70,628)	(70,628)	3
Net gain/(loss) unrealised	-	114,897	114,897	278,842
Market value 31 March 2025	3,883,191	3,724,936	7,608,127	7,552,532

Analysis of investments:

	2025 £	2024 £
Quoted Charity Common Investment funds		
Medium and long term	3,668,617	4,116,391
Liquidity fund	3,883,191	3,430,622
Cash on deposit	56,319	5,519
	7,608,127	7,552,532

During the year the Trustees transferred the proceeds of the medium term portfolio to the bank. Income was also transferred to the liquidity fund , with drawdowns later in the year.
Interest is added to the liquidity portfolio each month.

13 DEBTORS

	2025 £	2024 £
Gift Aid recoverable	20,183	4,970
Prepayments & accrued income	701,775	841,121
Trade Debtor	206,691	-
	928,649	846,091

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.

14 LIABILITIES

	2025 £	2024 £
Research grants not yet claimed	2,878,651	3,314,248
Accruals	29,364	27,784
Other creditors	180,735	75,126
Due within 12 months	3,088,750	3,417,158
Research grants due after 12 months	3,058,785	3,000,554
	6,147,535	6,417,712

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 funds represents money set aside by the Trustees for future research grants and for the #Every1EndingEpilepsy, a programme with the vision to radically advance the treatment and prevention of epilepsy, including the transition costs of becoming an institute.

	Designated Funds				
	Research Fund 2025 £	#Every1Ending Epilepsy 2025 £	Restricted Fund 2025 £	General Fund 2025 £	Total Unrestricted Funds 2025 £
Balance as at 1 April 2024	3,084,303	193,969	-	900,000	4,178,272
Net outgoing resources	-	-	167,264	(1,277,664)	(1,110,400)
Transfer between funds	(1,226,431)	(193,969)	(167,264)	1,587,664	-
Balance as at 31 March 2025	1,857,872	-	-	1,210,000	3,067,872

Unrestricted Funds 2024

	Designated Funds			
	Research Fund 2024 £	#Every1Ending Epilepsy 2024 £	General Fund 2024 £	Total Unrestricted Funds 2024 £
Balance as at 1 April 2023	2,213,953	280,218	900,000	3,394,171
Net incoming resources	166,322	(86,249)	704,028	784,101
Transfer between funds	704,028	-	(704,028)	-
Balance as at 31 March 2024	3,084,303	193,969	900,000	4,178,272

16 RESTRICTED FUNDS

	1 April 2024 £	Incoming Resources £	Resources Expended £	Transfers 2025 £	31 March 2025 £
Research grants	-	367,178	(199,914)	(167,264)	-
Research Events	-	11,230	(11,230)	-	-
Shape Network	-	10,890	(10,890)	-	-
	-	389,298	(222,034)	(167,264)	-

The Institute supports a wide range of research, from experimental studies of epilepsy, including laboratory research of the cellular and molecular mechanisms of epilepsy, to novel diagnostics and treatments for the clinical management of people living with epilepsy. Transfers represent expenditure incurred in a previous year from unrestricted funds, or small overspends against a restricted fund.

The Shape Network is a community of people affected by epilepsy who are dedicated to influencing research. Income was also received as contributions towards research events and symposia.

Restricted Funds 2024

	1 April 2023 £	Incoming Resources £	Resources Expended £	Transfers 2024 £	31 March 2024 £
Research Grants	-	1,513,851	-	(1,513,851)	-
Priority Setting Partnership	-	20,000	(20,000)	-	-
Aisling Burnard Award	-	150	(302)	152	-
Shape Network	-	15,000	(20,092)	5,092	-
Celine Newman Bursary	1413	-	(3,360)	1,947	-
	1,413	1,549,001	43,754	(1,506,660)	-

17 ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted Funds 2025 £	Restricted Funds 2025 £	Total Funds 2025 £
Total assets	9,215,407	-	9,215,407
Current liabilities	(3,008,750)	-	(3,008,750)
Creditors falling due after more than 1 year	(3,058,785)	-	(3,058,785)
	3,067,872	-	3,067,872

Analysis of net assets between funds 2025

	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total Funds 2024 £
Total assets	10,595,984	-	10,595,984
Current liabilities	(3,417,158)	-	(3,417,158)
Creditors falling due after more than 1 year	(3,000,554)	-	(3,000,554)
	4,178,272	-	4,178,272

18 RELATED PARTY TRANSACTIONS

The field of epilepsy research is highly specialised and for the Epilepsy Research Institute UK to function effectively it is vital that leading practitioners 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 Institute UK, but they must declare any conflicts of interest concerning grant applications and are excluded from any discussion regarding the merits of such applications.

In 2025, there was an extension to a co-funded award with Angelini Pharma of £199k was made to Trustee Professor Mark Richardson as lead applicant. This was awarded via the Institute, but the whole amount was funded by Angelini Pharma with monetary contribution from the Institute. Also in 2025, there was one new award where Institute President Helen Cross is a project collaborator. This is based at the University of Glasgow and entitled 'VISDOM-AI: Video-based Infantile epileptic Spasms Detection from bOdy Movements using AI'. As only funded in March 2025, no payments were paid out on the award during 2024-25. For these awards, no direct salary or salary contribution was paid for the Trustee/ President's involvements.

During 2024-25, the University of Liverpool were reimbursed for time for Professor Anthony Marson spent with the Institute in connection with his role as Institute Programme Director. In 2024-25 this was £21,400 (2023-24: £32,795). This reimbursement of the role ceased in September 2024, although Professor Marson has continued in a voluntary capacity.

In terms of similar projects in the previous year; in 2024, no new grants were awarded to Trustees as Lead Applicants. However, there were three new awards where Trustees were listed as a co-applicant, supervisor or co-investigator. For these awards, no direct salary or salary contribution was paid for the Trustee's involvements. These included: Professor Matthew Walker – Co-applicant for the project 'Development of a breath test for the diagnosis of epilepsy and the prediction of seizures' Professor Anthony Marson – Co-investigator for the North West Doctoral Training Centre Professor Anthony Marson – Co-investigator for the project 'An international study to investigate and optimise the safety of discontinuing Valproate in young men and women with epilepsy'.

19 LEASE COMITMENTS

A lease for office accommodation was taken out on 20 Sept 23 with the Royal College of Anaesthetists.

The lease is for 3 years to 17 Sept 2026 but will be terminated on 31 Mar 26. The following amounts are due:

April 25 - Mar 26 £50,102

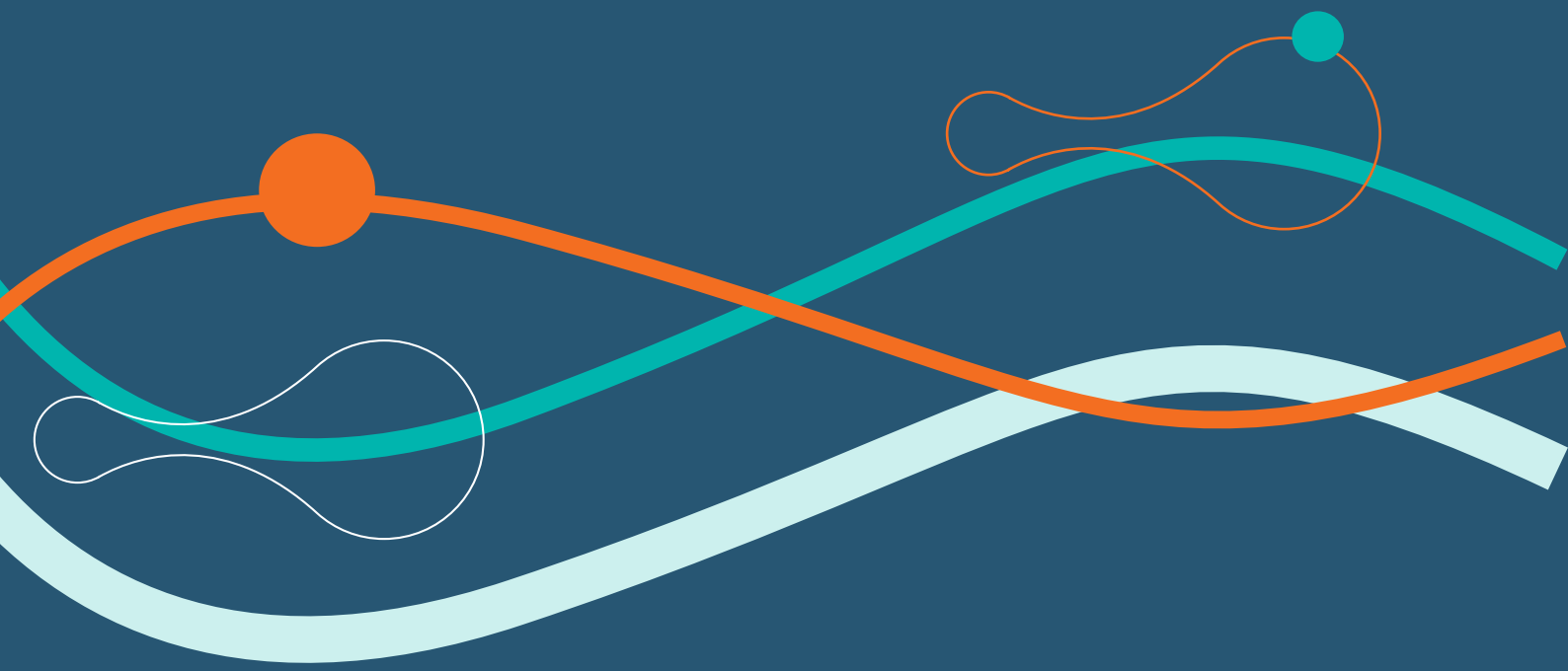
20 STATEMENT OF FINANCIAL ACTIVITY FOR THE YEAR ENDED 31 MARCH 2024 (PRIOR YEAR)

(Including the Income & Expenditure Account)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Income from:			
Donations and legacies	1,816,004	70,150	**1,886,154**
Grants	-	1,478,851	**1,478,851**
Other trading activities	3,608	-	**3,608**
Investments	226,493	-	**226,493**
Realised gains on investments	3	-	
Total Income	2,046,108	1,549,001	**3,595,109**
Expenditure on:			
Cost of raising funds			
Raising Funds	177,658	-	**177,658**
Charitable activities			
Research grants committed	1,999,070	-	**1,999,070**
Other research activities	870,782	43,753	**914,535**
Total charitable expenditure	2,869,852	43,753	**2,913,605**
Total expenditure	3,047,510	43,753	**3,091,263**
Net unrealised gains / (losses) on investments	278,842	-	**278,842**
Net income/(expenditure) for the year	(722,560)	1,505,248	**782,688**
Transfers between funds	1,506,661	(1,506,661)	-
Net movement in funds for the year	**784,101**	**(1,413)**	**782,688**
Reconciliation of funds:			
Total funds brought forward on 1 April	3,394,171	1,413	**3,395,584**
Total funds carried forward at 31 March	4,178,272	-	**4,178,272**

TOGETHER, WE WILL RADICALLY ADVANCE RESEARCH INTO EPILEPSY

For more information about our work, please visit our website: epilepsy-institute.org.uk/





"To anyone considering leaving a legacy, I would say: research has the power to transform lives, and your support can make that possible."
John, supporter

Once you've remembered your loved ones, would you consider investing in crucial epilepsy research by leaving a gift in your Will to the Epilepsy Research Institute?

Your gift could mean a life free from epilepsy for the one in 100 people living with the condition now and in generations to come.

For more information on leaving a gift in your Will to the Epilepsy Research Institute, download our guide using the QR code or contact Jo at legacyteam@epilepsy-institute.org.uk.

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A company limited by guarantee
Registered in England number 4873718
Registered charity number 1100394

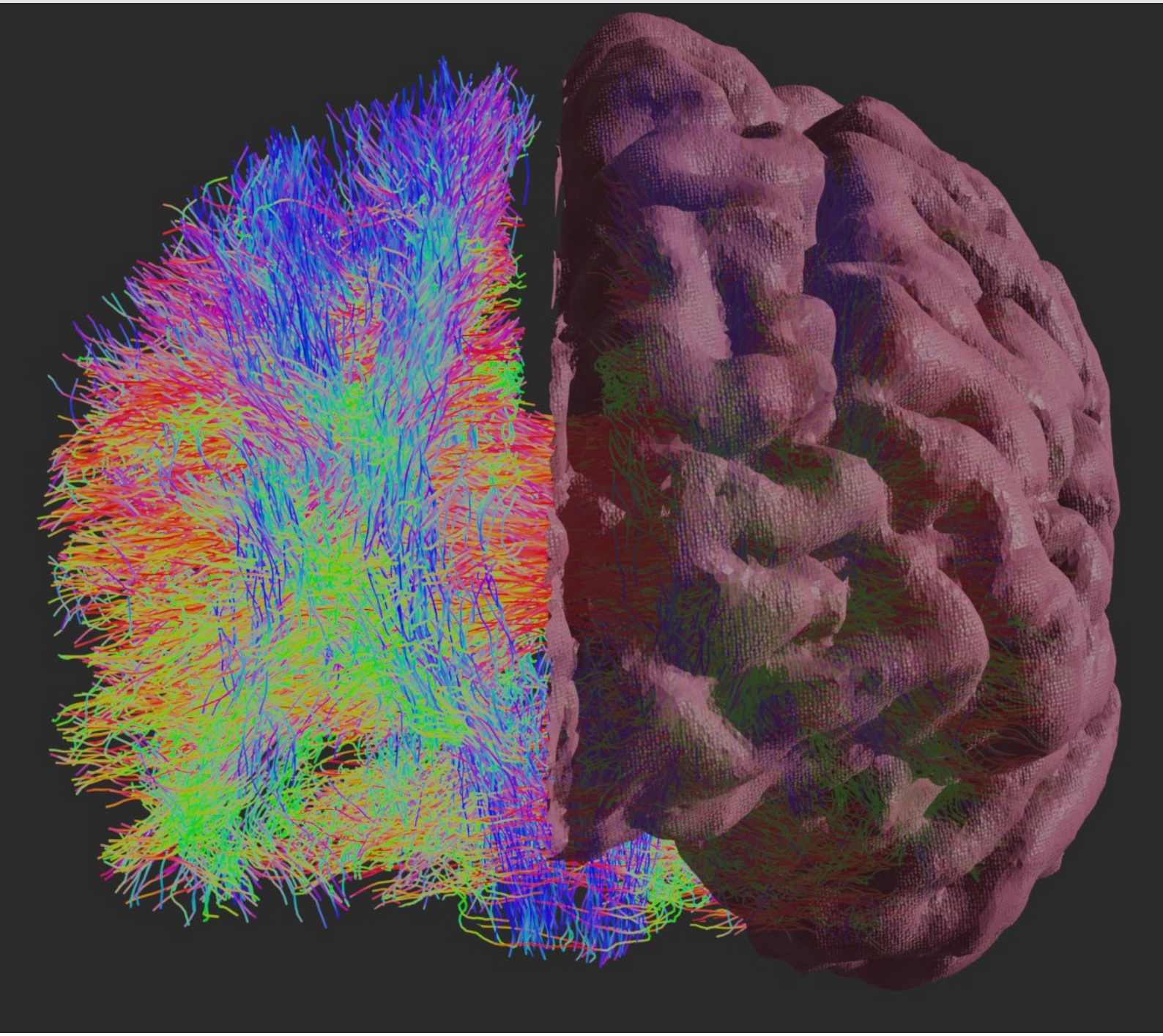
EPILEPSY RESEARCH INSTITUTE UK

England & Wales - Charity number 1100394

Accounts

RADICALLY ADVANCING RESEARCH INTO EPILEPSY

Annual Review 2023-24



EPILEPSY RESEARCH INSTITUTE UK

epilepsy-institute.org.uk



"Epilepsy research has saved so many lives, including mine. If I was still on the same medication I was on a few years ago, I'm not sure where I'd be right now. My partner George is just as passionate as I am about raising money for this vital research to help beat epilepsy."
Georgi, Epilepsy Research Institute supporter

CONTENTS

Page 4	Our year in numbers
Page 6	Welcome from our Chair and Chief Executive
Page 8	Our vision, mission and values
Page 11	Our research programme
Page 12	Neurodevelopment
Page 13	Advanced Therapeutics & Disease Modification
Page 14	Mortality, Morbidity & Risk
Page 15	Reproduction & Hormones
Page 16	Capacity Building
Page 17	Enabling Technologies
Page 19	Our strategic priorities
Page 20	What we did to convene, connect and capacity build
Page 22	What we did to drive strategic investment
Page 24	What we did to fund research
Page 30	What we did to develop partnerships and collaborations
Page 32	What we did to action the priorities of people affected by epilepsy
Page 34	Our research impact and performance
Page 38	Our supporter highlights
Page 42	Trustees' report and financial statements

OUR YEAR IN NUMBERS

over
£2 million

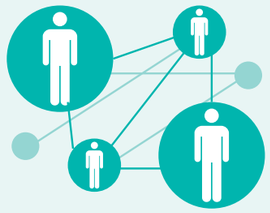
record research investment as part of our 2024 Research Awards, involving 58 researchers and collaborators on 14 projects



The official launch of the Epilepsy Research Institute at a reception at **10 DOWNING ST**

over
350

researchers signed up to The Hub – our online portal for researchers working in the field of epilepsy and associated conditions



over
500

people now part of the Shape Network – the UK's largest network of research-interested people affected by epilepsy

The Institute featured in a segment on the BBC's The One Show along with one of our Founding Partners, Young Epilepsy, as part of International Epilepsy Month

over
300

people supported vital epilepsy research through challenge events or fundraisers

£1.47 million



awarded to the Institute from the UK Government's Medical Research Charities Early Career Researchers Fund

£5.41

leveraged in follow-on funding for every £1 invested in research by the Institute

WELCOMING OUR **NEW CHIEF EXECUTIVE**

In January 2024, Rosemarie Pardington began her role as Chief Executive of the Epilepsy Research Institute, taking over from outgoing Chief Executive Maxine Smeaton. Rosemarie was Deputy CEO at Young Epilepsy and previously held other executive roles at Leonard Cheshire Disability.

The Institute's Chair Professor Matthew Walker stated, "We are delighted and thrilled to welcome Rosemarie as our new Chief Executive. Rosemarie brings a wealth of experience, and we look forward to having her lead the team as we grow the epilepsy research ecosystem to achieve the Institute's mission.

"The Board of Trustees are also immensely grateful to our outgoing Chief Executive, Maxine, who led the transformation of Epilepsy Research UK to the Epilepsy Research Institute – the world's first national research institute dedicated to epilepsy."



WELCOME FROM **OUR CHAIR AND CHIEF EXECUTIVE**



Professor Matthew Walker
Chair of Trustees



Rosemarie Pardington
Chief Executive

This is our first annual report as the Epilepsy Research Institute*. We've been both delighted and humbled by the epilepsy community's response to the formation of the Institute. Families, epilepsy charities, researchers and healthcare professionals have all shown incredible support, which has reaffirmed our commitment to our mission.

Epilepsy is far too big a challenge for one organisation to tackle alone. As the Epilepsy Research Institute, we have become the central hub for the epilepsy research community. We have seen how research institutes have advanced science, changed research landscapes and built capacity in many other fields. Even though we were only formally established in October 2023, we've already seen the huge potential for doing the same for epilepsy.

This year, we have invested over £2 million in research by funding 14 grants, including six Fellowship Awards focused on capacity building epilepsy research in the UK. This is our largest ever annual research investment, and while we are thrilled to be in a position to fund this amount of research, we recognise the urgent need to unlock greater strategic investment.

As the Institute, we are now able to talk with a united voice to influence policymakers and funders, and use that voice to secure strategic investment in epilepsy research. This is the key to correcting the years of chronic underfunding that has held epilepsy research back. In our first year, we were delighted to receive funding from the UK Government's Medical Research Charities Early Career Researchers Support Fund. With the publication of our strategy for research later this year, we will be looking to unlock more investment.

*Until October 2023, we were Epilepsy Research UK, but for ease of reading, throughout this report we refer to ourselves as Epilepsy Research Institute or, simply, the Institute.

Partnerships and collaboration remain at the heart of our work and this year we were delighted to partner with Dravet Syndrome UK to co-fund two Fellowships focusing on this severe form of epilepsy. We were also proud to co-fund a Clinical Research Training Fellowship (CRTF) at the University of Cambridge with the Medical Research Council (MRC).

We know that by working together, pooling resources and sharing ideas and knowledge, we will reach our goals quicker. Hence, the Board of Trustees recognised that in 2023–24 we needed to invest in the structure and foundations of the new Institute, in order to achieve our ambitious plans.

Our research programme is based on, and informed by, the UK Epilepsy Priority Setting Partnership (PSP) Top Ten priorities. In this report we have detailed the six key research themes that make up our programme and which will have the biggest impact for people affected by epilepsy. Significant progress has already been made with implementation and we have recruited 'theme leads' who will head up a dedicated task force of leading scientists and clinicians. Later in the report, we share some of the ambitious plans we have in place for each of the individual themes.

Our focus this year has been on funding and supporting early career researchers, which we believe will make a huge difference to the epilepsy community. The significant steps we have taken will strengthen the research infrastructure and help to develop the research ecosystem. It is thanks to our supporters that all this vital work has taken place.

In this challenging and uncertain financial environment, we are extremely grateful for the ongoing commitment of our supporters. We recognise that the cost of living continues to bite, so to all those who make regular or one-off gifts, those who've taken on challenge events or remembered us in their Will, thank you to you and your families. Your support really does make a huge difference.

We know for many in our epilepsy community, life continues to be a struggle. Far too many live with uncontrolled seizures, far too many have their quality of life seriously curtailed by a multitude of side effects, and far too many have their lives cut short.

The answers to the problems we face will be found in research. We're working towards a future when an epilepsy diagnosis also comes with a range of personalised treatment options. Ultimately, we hope that one day all forms of epilepsy are preventable and we achieve our vision of a life free from epilepsy.

With the formation of the Institute and the promise it brings, we stand at the threshold of a new era in epilepsy research. A time when we refuse to accept the historic underfunding that has hindered progress for far too long. We are focused on our mission and have a clear plan for the coming years.

We offer our heartfelt thanks to every one of our Founding Partners, supporters, volunteers, colleagues and partners who have contributed to the Institute. Achieving our goals is only possible through our collaborative effort. This is just the start of our journey.

Professor Matthew Walker, Chair of Trustees
Rosemarie Pardington, Chief Executive

OUR **VISION, MISSION AND VALUES**

Our Vision
A life free from epilepsy

Our Mission
To radically advance research into epilepsy

Our Values

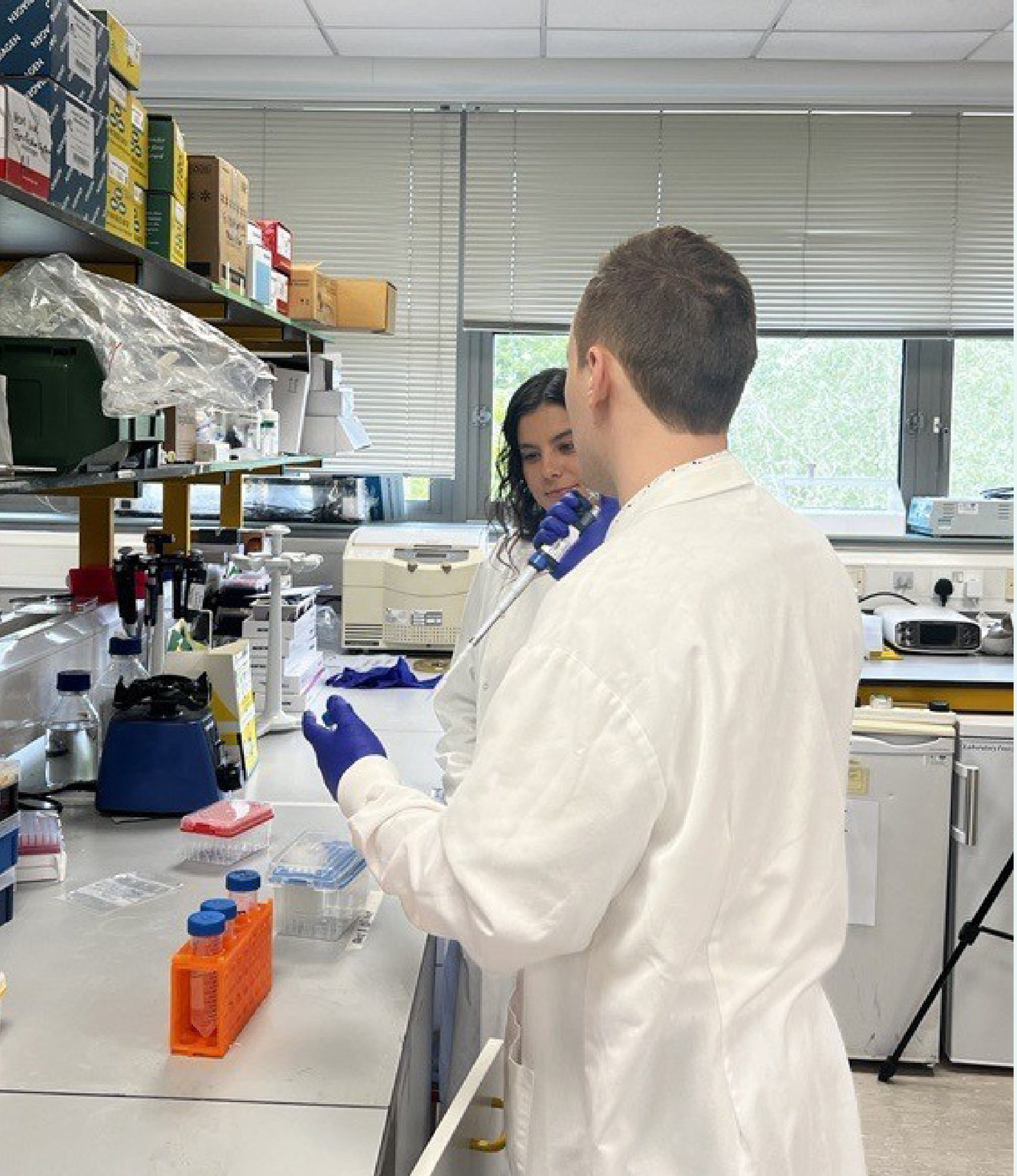
INTEGRITY	We are open and transparent about all aspects of our work and employ the upmost candour in our focus to '*radically advance research into epilepsy*'.
COLLABORATIVE	We appreciate that it is only by working together we will achieve our vision of '*a life free from epilepsy*'. Our teamwork and partnerships reflect our integrity, professional approach and trustworthiness.
HONESTY	We expect a high standard of excellence, supporting the best science with our systematic and rigorous approach to all of our work.
INNOVATIVE	We are courageous and ambitious to enable ground-breaking research and welcome innovative and creative ideas.
DIVERSITY & INCLUSION	We are respectful of all the people working with, and for us, including people living with epilepsy, researchers, collaborators and our supporters, fostering teams across diverse cultures and backgrounds and valuing their views and input.

Our Founding Partners

Young Epilepsy · EPILEPSY ACTION · epilepsy scotland · ILAE International League Against Epilepsy



Our joint reception with Young Epilepsy at The Francis Crick Institute, May 2023



OUR RESEARCH **PROGRAMME**

Our research is focused on the causes, prevention and treatment of epilepsy and its associated conditions.

Alongside funding ground-breaking studies, we are also committed to strengthening the epilepsy research ecosystem by driving strategic investment and developing partnerships and collaborations between academia, the NHS, industry, funders, patient groups and people affected by epilepsy.

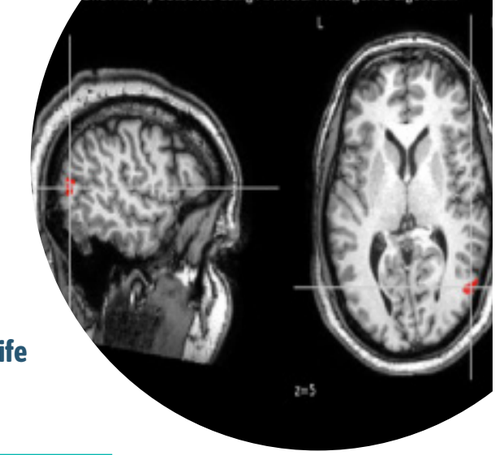
Guiding and directing our work are the research priorities of those affected by epilepsy. Based on these priorities, our research programme focuses on six key themes designed to make the biggest difference to their lives:

- Neurodevelopment
- Advanced Therapeutics & Disease Modification
- Mortality, Morbidity & Risk
- Reproduction & Hormones
- Capacity Building
- Enabling Technologies

Under each theme are specific ambitions and priority areas for researchers and research funders. This year, we recruited three co-leads for each research theme, who will head up a task force of leading scientists and clinicians. Together, their job is to develop a comprehensive strategy to radically advance research in these six key areas. Our dedicated teams were only recently formed, but they have already made significant progress. Each group is now focused on finalising the content and priorities for the strategy report for research, due to be published in Autumn 2024.

The pages that follow provide an overview of the six themes, including our research aims and priorities.

NEURODEVELOPMENT



Aim: To drive novel multidisciplinary research into the causes of epilepsy and its lifelong relationships with neurodevelopmental conditions, accelerating the development of interventions and improving quality of life for all affected.

Background

There is a complex interplay between seizures, cognition, memory and mental health. People with epilepsy are at increased risk of developing depression and associated anxiety disorders. For those experiencing cognitive and behavioural problems, in most cases, they are caused by co-occurring neurodevelopmental disorders, such as autism and attention-deficit hyperactivity disorder (ADHD).

However, despite the strong link, we know little about the common underlying causes and how to best treat seizures in autistic people. Epilepsy in autistic people is also more likely to be resistant to standard treatments, and it is one of the leading causes of early death among this group.

By increasing our knowledge of the link between epilepsy and other neurodevelopmental conditions, and by improving our understanding of the overlap between these disorders, we'll be able to develop treatments and strategies to prevent, treat and avoid the wider consequences of epilepsy.

Research ambitions

- To identify the mechanisms underpinning neurodevelopmental forms of epilepsy and use this knowledge to inform the development of early interventions and precision therapies to improve quality of life.
- To characterise the bidirectional relationship(s) between epilepsy and neurodevelopment and use this knowledge to reduce/prevent comorbidities and improve brain health.

Neurodevelopment Theme Leads



Clinical Co-Lead
Professor Sameer Zuberi
University of Glasgow

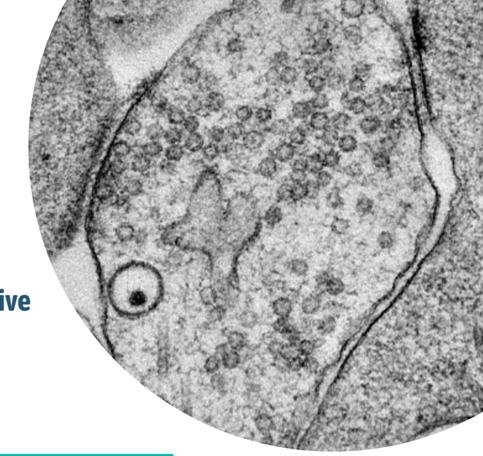


Fundamental Science Co-Lead
Professor Juan Burrone
King's College London



Early Career Lead
Dr Felix Chan
Aston University

ADVANCED THERAPEUTICS & DISEASE MODIFICATION



Aim: To facilitate and enable the development of innovative therapies and interventions across the translational pipeline for the treatment and prevention of epilepsy.

Background

Epilepsy is a diverse condition, with many underlying causes, seizure types and responses to treatments, all of which can vary greatly among individuals. This variability poses a significant challenge in epilepsy management, but also presents an opportunity for personalised treatment approaches in genetics, pharmacology and neuroimaging.

It is vital that we find treatments for drug-resistant epilepsy that effectively control seizures while minimising side effects. By understanding the intricate causes of epilepsy and the pathways involved in seizure generation, researchers can design medications that specifically target these pathways in a way that works for all people with epilepsy.

Research ambitions

- To develop a translational research framework to identify and test new treatments for epilepsies with high unmet need, spanning basic discovery to clinical trials.
- To identify treatments that prevent the development of and/or reduce the severity of epilepsy.
- To develop productive links with industry and regulators to speed the translation of candidate therapeutics.

Advanced Therapeutics & Disease Modification Theme Leads



Clinical Co-Lead
Professor Michael Johnson
Imperial College London

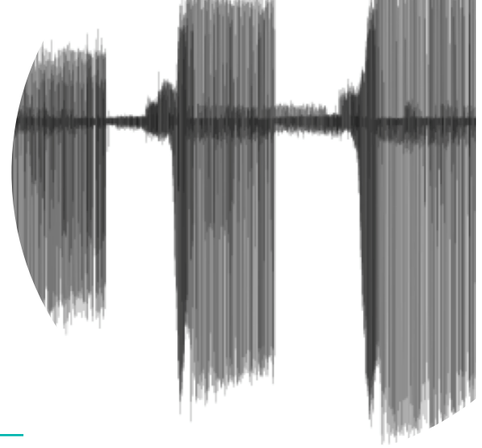


Fundamental Science Co-Lead
Professor Gabriele Lignani
UCL Queen Square Institute of Neurology



Early Career Lead
Dr Gareth Morris
University of Manchester/UCL

MORTALITY, MORBIDITY & RISK



Aim: To accelerate research through multidisciplinary approaches to identify risk factors, reduce morbidity and prevent epilepsy-related deaths.

Background

Reducing the risk of mortality is of great importance if we are to halt the harm caused by epilepsy, not just to those living with the condition, but also their family and friends.

People living with epilepsy are up to three times more likely to die prematurely than those without the condition. Every day, three people die from epilepsy-related deaths in the UK alone. Many of these deaths are potentially avoidable, but to prevent them we need to better understand the causes and be able to identify those who are at risk.

The reasons why the mortality of people with epilepsy is significantly increased, even years after seizure onset, are not fully known. Likewise, the mechanisms by which sudden unexpected death in epilepsy (SUDEP) occurs are poorly understood.

We will drive forward work that investigates the causes of SUDEP and other epilepsy-related deaths by identifying risk factors and developing interventions to overcome them. This programme of work seeks to substantially reduce the mortality and morbidity of epilepsy, and will enable risks associated with the condition to be more effectively managed.

Research ambitions

- To prevent all avoidable epilepsy-related deaths.
- To identify pathways and mechanisms that can be targeted to prevent SUDEP.
- To identify and stratify people with epilepsy to reduce their risk of mortality and/or morbidity.
- To understand the bidirectional relationships between epilepsy and other mind–brain health conditions, using this to inform treatments and improve quality of life for people with epilepsy across the lifespan.
- To understand the comorbidity of complex genetic and acquired epilepsies.

Mortality, Morbidity & Risk Theme Leads



Clinical Co-Lead
Professor Arjune Sen
University of Oxford



Fundamental Science Co-Lead
Dr Rob Wykes
University of Manchester/UCL



Early Career Lead
Dr Amol Bhandare
University of Warwick

REPRODUCTION & HORMONES



Aim: To advance and accelerate research into the study of reproductive health and hormones in epilepsy across the lifespan, working across the translational pipeline to deliver impactful patient benefit.

Background

While many anti-seizure medications are teratogenic – they cause malformations in babies when they are exposed in utero – we do not understand the mechanisms by which malformations occur.

Nor do we understand the risk posed to children fathered by men taking anti-seizure medications, or if there are transgenerational effects.

For both men and women living with epilepsy, deciding to start a family can still cause great anxiety and stress. We need to better understand the mechanisms by which anti-seizure medicines cause harm to the babies of people with epilepsy. To address this anxiety, and the risk to future generations, we must develop strategies and newer treatments that prevent harm.

Research ambitions

- To inform the development of safer anti-seizure medicines for people with epilepsy who wish to have families.
- To enable reproductive decision-making for men and women with epilepsy by expanding translational research to build evidence-based risk information and how to deliver this.
- To find ways to reduce international rates of children born with intellectual disabilities and congenital abnormalities related to the use of anti-seizure medications.
- To decrease the rates of deaths in people with epilepsy in their reproductive years.
- To overcome the failure to treat seizures influenced by hormonal changes and the associated risks (e.g. mental health).
- To mitigate the impact of epilepsy and anti-seizure medication on male and female reproductive hormones throughout the lifespan.

Reproduction & Hormones Theme Leads



Clinical Co-Lead
Dr Rebecca Bromley
University of Manchester



Clinical Co-Lead
Dr Janine Winterbottom
The Walton Centre
NHS Foundation Trust



Early Career Lead
Dr Faye McLeod
Newcastle University

CAPACITY BUILDING



Aim: To transform the epilepsy research ecosystem in the UK and internationally through informed, strategic interventions to elevate and expand multidisciplinary networks, generate opportunities and foster a progressive and inclusive research culture.

Background

There are an estimated 600 researchers currently working in epilepsy in the UK, fewer than 10% the number of researchers working in dementia (6,100 researchers).

By strengthening the network of epilepsy researchers in the UK through workshops, events, special interest groups, we will enable new multidisciplinary collaborations, foster research partnerships and drive greater research investment. We also aim to extend the epilepsy researcher network to include researchers working in associated conditions and in overlapping methodologies. Crucially, we also need to ensure people affected by epilepsy are at the heart of all research and shape how studies are designed and delivered.

Research ambitions

- To elevate and expand research into epilepsy to ensure a thriving, inclusive ecosystem that attracts and retains the brightest minds.
- To facilitate access to equipment and expertise to reduce barriers to epilepsy research.
- To support students and early-career researchers working in epilepsy research with practical training/ learning opportunities and mentorship.
- To facilitate collaborative multidisciplinary research networks within the UK and worldwide, including with industry, funders, NHS, healthcare providers, policymakers and people living with/affected by epilepsy.
- To increase the visibility of epilepsy research – through campaigns, policy-facing work, patient and public engagement, and celebrating achievements.

Capacity Building Theme Leads



Clinical Co-Lead
Dr Sukhvir Wright
Aston University



Fundamental Science Co-Lead
Professor Torsten Baldeweg
UCL Great Ormond Street Institute of Child Health



Early Career Lead
Dr James Mitchell
The Walton Centre NHS Foundation Trust

ENABLING TECHNOLOGIES



Aim: To leverage technologies and foster collaborations to enhance innovation and accelerate impact for patient benefit in ways that extend beyond the existing research and clinical landscape.

Background

For research to deliver life-changing breakthroughs, it needs an environment where it can flourish. Knowledge and information require an infrastructure that supports research, encourages shared learning, nurtures talent and promotes impact.

We must harness enabling technologies to ensure research and clinical data are appropriately consented, widely available and open to researchers, helping to foster collaborations and grow the pipeline of epilepsy researchers

Research ambitions

- To ensure that every person with epilepsy can benefit from currently available research and clinical technologies.
- To establish a world-leading environment for the rapid translation of promising technological advances towards direct applications in epilepsy.
- To create a frictionless research landscape in the UK for developing novel technologies that address urgent priorities in epilepsy.

Enabling Technologies Theme Leads



Clinical Co-Lead
Professor Mark Richardson
King's College London



Data Co-Lead
Professor John Terry
University of Birmingham



Early Career Lead
Dr Richard Rosch
King's College London

THE NEXT STEPS FOR EACH RESEARCH THEME

- Recruit taskforces – including relevant experts, specialists and members of the Shape Network – to inform and help develop their work.
- Confirm and cost our research priorities for coming years.
- Implement a strategy for research.

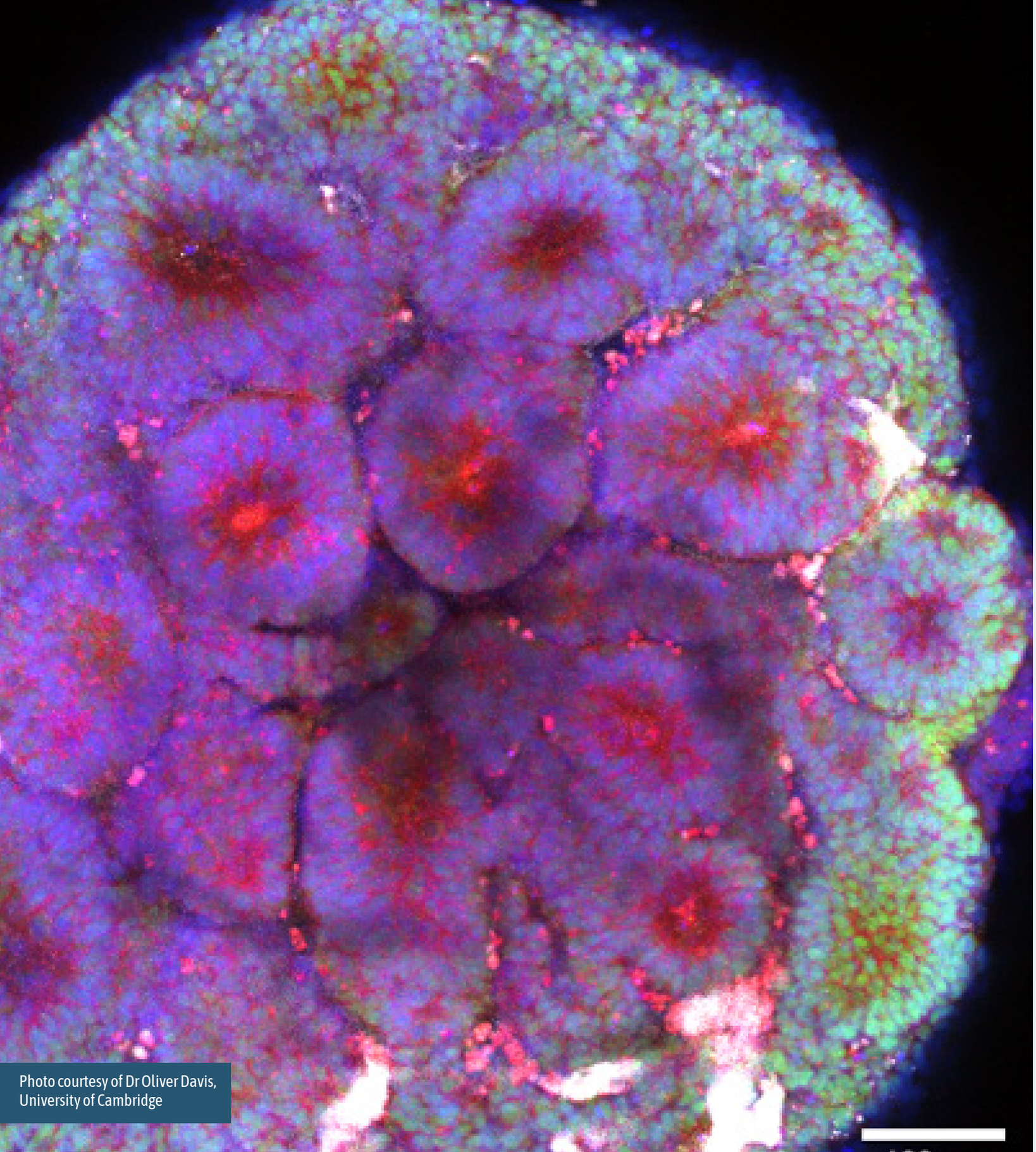


Photo courtesy of Dr Oliver Davis, University of Cambridge

OUR STRATEGIC **PRIORITIES**

The Epilepsy Research Institute will:

Connect, convene and capacity build the epilepsy research ecosystem to create a strong, vibrant and well-funded ecosystem where research can flourish.

Drive strategic investment in epilepsy research to radically advance research. We want to see science deliver for people living with epilepsy.

Fund research into epilepsy and associated conditions to increase understanding of causes and mechanisms to accelerate research innovations in prevention and treatment.

Develop research partnerships and collaborations between academia, the NHS, industry, funders, patient groups and people affected by epilepsy.

Advocate for the research priorities of people affected by epilepsy to ensure that people affected by epilepsy are central to everything we do and help shape research.

The pages that follow highlight the work we've done to address our priorities in 2023-24.

WHAT WE DID TO **CONVENE, CONNECT AND CAPACITY BUILD THE EPILEPSY RESEARCH ECOSYSTEM**

To strengthen the research ecosystem, we are building an infrastructure that supports research, encourages shared learning and nurtures talent. The free exchange of knowledge and information is vital to foster collaborations and attract early career researchers.

2024 Research Awards focused on capacity building

Our 2024 Research Awards were focused on supporting early career researchers, to attract the most promising scientists to epilepsy research and safeguard future capacity in this field.

Thanks to the dedication and generosity of our supporters, we were able to invest over £2million into our 2024 Research Awards – our biggest ever annual investment. The Awards (see page 24) will fund 14 new projects involving 58 researchers and collaborators across 12 institutions in the UK and internationally.

Survey carried out to assess capacity in epilepsy research

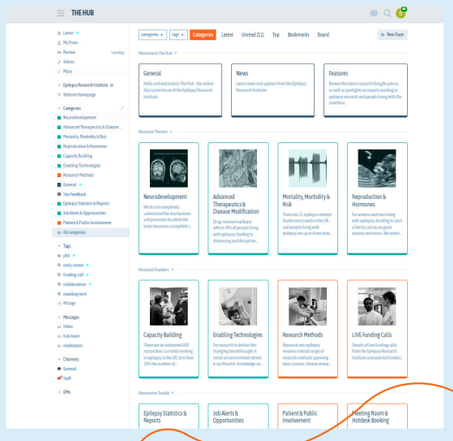
At the end of March 2024, the Institute launched a survey to assess the current capacity in epilepsy research. Carried out as part of the Institute's Capacity Building strategic theme, the survey will help us gain a better understanding of the research ecosystem, including the facilitators and barriers to engaging with and undertaking research.

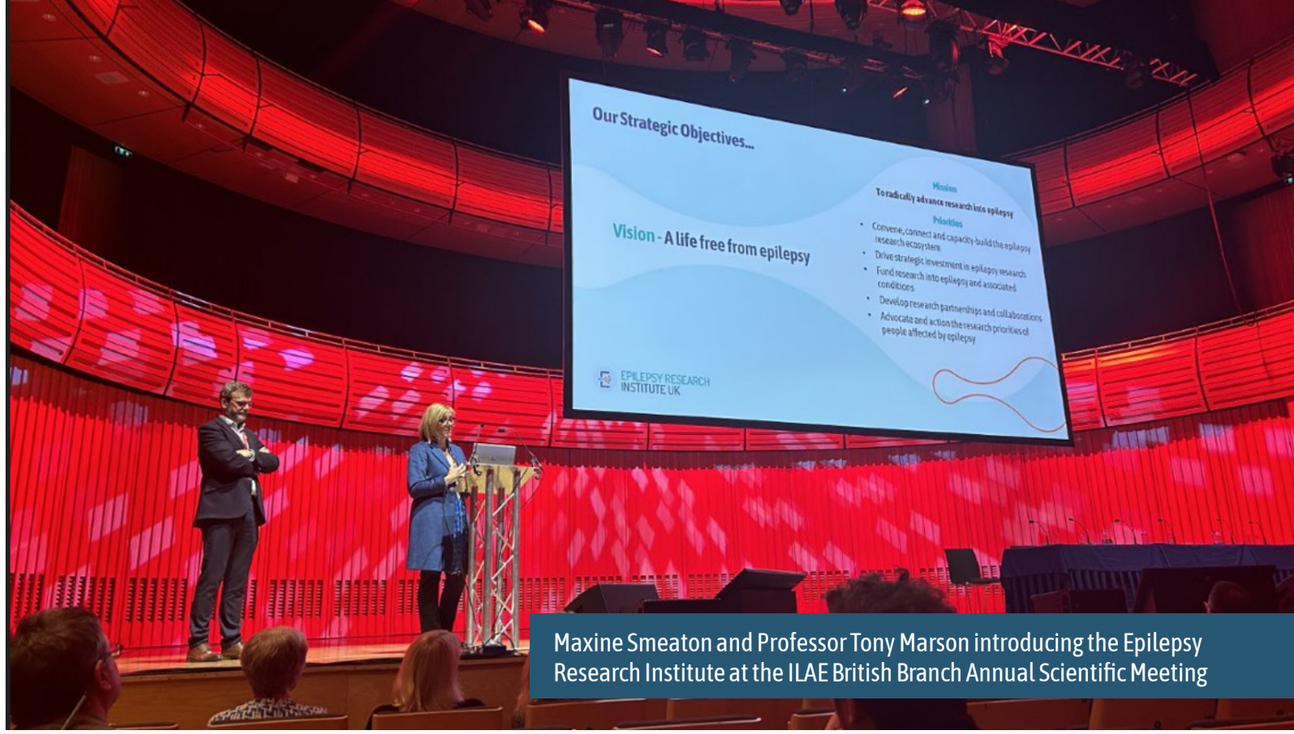
Results from this survey will help inform the Capacity Building theme's work by clarifying the current capacity and ensuring we measure our success from the correct baseline.

Launched 'The Hub' – the online portal for epilepsy researchers

In October 2023, we launched The Hub, our online discussion portal for researchers working in epilepsy and its associated conditions. Through The Hub, researchers can connect and discuss the Institute's research programmes, as well as access resources, webinars and conferences. Researchers are also able to see upcoming networking and funding opportunities, job alerts and information on how our Shape Network members can inform research proposals and plans.

As at 31 March 2024, there were over 350 researchers signed up to The Hub, almost two-thirds of the estimated number of researchers in epilepsy in the UK.





Maxine Smeaton and Professor Tony Marson introducing the Epilepsy Research Institute at the ILAE British Branch Annual Scientific Meeting

Sharing vital knowledge and research findings

It is essential that research findings and breakthroughs are communicated and shared to further the understanding of epilepsy. We continued to ensure that information was freely shared with researchers, people affected by epilepsy, and funders through our e-newsletters, blog posts and news articles. In March 2024, we launched 'Epilepsy Research Institute Insights' webinars, featuring our funded researchers, world-leading experts and people affected by epilepsy. Over 160 researchers attended and watched the recording of the inaugural webinar, which focused on building capacity in epilepsy and featured the theme co-leads.

Space for researchers to work, share and collaborate

Researchers can now book space for workshops, meetings or simply a hotdesk at our new office in Holborn via The Hub – our online portal. The office space can be used for collaborative working and promotes shared learning.

ILAE British Branch Annual Scientific Meeting

Researchers, clinicians and healthcare professionals working in epilepsy came together in October 2023 for the International League Against Epilepsy (ILAE) Annual Scientific Meeting. Held in Gateshead, the conference saw the official launch of the Epilepsy Research Institute to the scientific community, including the announcement of the co-leads for the strategic themes.

At the conference, the Institute ran the regular Neurobiology of Epilepsy session, during which shortlisted early career researchers competed for the Cèline Newman Neurobiology of Epilepsy Award. Dr Laura Smith from Newcastle University was the winner of this year's award. Dr Smith is a postdoctoral Research Associate at the Wellcome Centre for Mitochondrial Research and was awarded for her presentation on 'Delineating the neuropathophysiological mechanisms underpinning refractory epilepsy in Alpers' syndrome'.

WHAT WE DID TO **DRIVE STRATEGIC INVESTMENT IN EPILEPSY RESEARCH**

Epilepsy research has been held back by insufficient investment and a fragmented research ecosystem. This underfunding has impacted every single person living with the condition, through delaying the discovery of new treatments and reducing quality of life. Our vision of a life free from epilepsy can only be achieved by driving strategic investment that will radically advance research.

Leveraging follow-on funding

We have an excellent track record, which is evidenced by every £1 invested by the Institute leveraging on average, £5.41 in follow-on-funding from other institutional funders.



Every £1 invested in research by the Epilepsy Research Institute has leveraged a further £5.41 in follow-on funding.

Supporting researchers with funding applications with our Shape Network PPIE group

The assessment process of this year's grant round was again supported by our Application Clinics. Researchers were encouraged to meet members of the Shape Network to discuss their proposed research. By involving people affected by epilepsy in the development stage of a proposal, we are supporting researchers to produce stronger applications.

Researchers at King's College London were awarded funding by the National Institute for Health and Care Research (NIHR) and the Medical Research Council (MRC) to investigate the causes of rare epilepsies. Central to this research will be the involvement of people affected by epilepsy through our Shape Network.

The Shape Network continues to grow, and as at 31 March 2024 we had over 500 members. The Institute is receiving an increasing number of enquiries from researchers around the country to work closely with network members to help inform and guide their research programmes.

Awarded £1.47m from Early Career Researcher Fund

The Institute was awarded £1.47 million from the UK Government's Medical Research Charities Early Career Researchers Support Fund. This investment in early career researchers will support the delivery of our research strategy and boost our efforts to grow the next generation of epilepsy research leaders.

Building relationships with funders

As part of the formation and announcement of the Epilepsy Research Institute, we have hosted large events in venues such as 10 Downing Street and The Francis Crick Institute. We were able to showcase our work and ambitions to the many potential funders and partners who were present at these receptions, laying out a clear plan to advance research and improve lives. Only through collaboration and strategic investment will we be able to drive research into epilepsy forward.

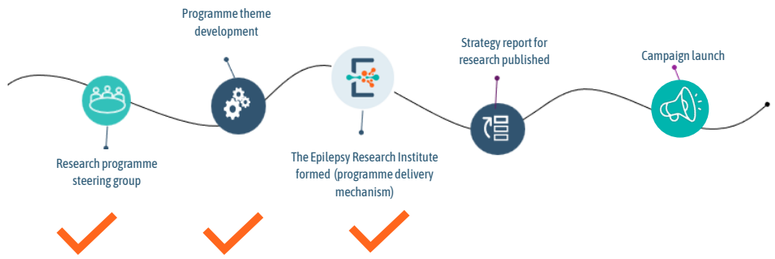




Development of our research strategy

As highlighted in the previous pages, the Institute's research programme is focused on six key themes: Neurodevelopment, Advanced Therapeutics & Disease Modification, Mortality, Morbidity & Risk, Reproduction & Hormones, Capacity Building and Enabling Technologies.

Through regular workshops, the research theme leads have begun to identify the priorities for each area and the actions required to advance research. Once this work is completed it will be published in a strategy for research later in 2024. Using the strategy, we will call on institutional funders and the Government to invest in research. Alongside this, the Institute will launch our national campaign, focused on promoting our strategic priorities and raising awareness of the impact of epilepsy and the promise of research.



Forging partnerships and collaborations

In 2023/24, we took significant steps in driving strategic investment through collaborations and partnerships with organisations such as the Medical Research Council (MRC) and Dravet Syndrome UK, with which we are co-funding three Fellowships with. Go to page 30 to read more about our partnerships and collaborations in 2023/24.

WHAT WE DID TO **FUND RESEARCH INTO EPILEPSY AND ASSOCIATED CONDITIONS**

This year, the Epilepsy Research Institute made a record research investment of over £2 million, funding 14 new projects involving 58 researchers and collaborators across 12 institutions in the UK and internationally. This includes the projects of seven PhD students within the North West Doctoral Training Centre. Thanks to the generosity and dedication of our supporters, this is our largest ever annual research investment.

Our 2024 Research Awards were focused on capacity building and supporting early career researchers. The Institute has a rigorous funding process involving members of the Shape Network – the UK's largest network of research-interested people affected by epilepsy. You can read more about the grant-awarding process in Annee's viewpoint article on the next page.

PROJECT TITLE	AMOUNT	LEAD APPLICANT	INSTITUTION
Cognition in people with epilepsy and their offspring: How does epilepsy and its treatment affect brain function?	£328,041	Dr Rebecca Bromley, Professor Simon Keller	University of Manchester and University of Liverpool
NETWORKS – Neuroscience-based Epilepsy Treatment With Optimised Retrospective Knowledge and Subcortical disconnection	£249,694	Mr Davide Giampiccolo	University College London
An international study to investigate and optimise the safety of discontinuing valproate in young men and women with epilepsy	£299,996	Dr Gashirai Mbizvo	University of Liverpool
Reprogramming of reactive glia into fast-spiking interneurons in a mouse model of mesial temporal lobe epilepsy	£299,862	Dr Nicolas Marichal Negrin	King's College London
Development of a breath test for the diagnosis of epilepsy and the prediction of seizures	£289,577	Dr Ilaria Belluomo	Imperial College London
Investigating chromatin misfolding as a pathogenic mechanism in neurodevelopmental disorders	£142,048	Dr Oliver Davis	University of Cambridge
Advancing precision medicine: genome engineering for on-demand gene therapy in Dravet syndrome	£222,752	Dr Jenna Carpenter	University College London
Understanding autonomic dysfunction in Dravet syndrome	£196,863	Dr Lisa Clayton	University College London
Total grants awarded	**£2,028,835**		

You can find more information on the pioneering projects we funded this year on the following pages. To watch video interviews with the researchers, please scan the QR code or visit: **epilepsy-institute.org.uk/eri/research/research-portfolio/**



VIEWPOINT

In this article, Annee Amjad – the Institute's Head of Research & Involvement – highlights the groundbreaking research we have invested in this year and shares more about the Institute's rigorous funding process.

This year's research awards were focused on capacity building – one of our six key strategic priorities. We accepted applications for Emerging Leader Fellowship Awards, to propel promising early career researchers forward in their careers, and Doctoral Training Centres, which are a series of linked PhD projects with a programme of training and support.

"We are extremely excited by the research projects awarded this year, which have a combination of fundamental, clinical and data science, all with the potential to improve the lives of people affected by epilepsy."

The process began in October 2023 when researchers submitted an Expression of Interest to briefly outline their proposal. Researchers were then invited to take part in an 'Application Clinic' with members of the Institute's Shape Network. The Shape Network is the Institute's dedicated community of people affected by epilepsy who are interested in learning about, participating in and shaping research.

During the clinics, researchers explained their proposals and Shape Network members had the chance to discuss the project and provide feedback. Members commented on how important they felt the topic was, any concerns they had about the proposal, any challenges they could foresee and anything they felt the researcher had not considered. Researchers then had the opportunity to address the discussions with the Shape Network and incorporate their feedback before submitting their final applications.

Following submission, applications are peer reviewed by at least three independent academics and clinicians with relevant experience.

The next stage is where our Scientific Advisory Committee (SAC) comes in. The SAC is our panel of leading neurologists, neuroscientists and epilepsy researchers who make recommendations about which projects should be funded to the Board of Trustees.

The SAC read through all the applications, Shape Network comments, peer reviews, and the applicants' rebuttal. Taking all of these into account, they carefully consider and rank the Doctoral Training Centre applications, recommending one project for funding to the Board of Trustees. This year, the SAC were extremely excited about the North West proposal, which has a focus on cognition in epilepsy, an understudied area included in number four of the top 10 priorities for research into epilepsy.

The Fellows have an extra stage in the application process and shortlisted researchers are invited to an in-person interview with members of the SAC and Shape Network. This stage is scored by the SAC and a ranked list of applications is submitted to the Board for their consideration and final decision. We were delighted that this year, as part of her induction, our new Chief Executive Rosemarie attended as an observer, to get a true understanding of how robust the process is.

It's extremely exciting to have awarded this funding after such a rigorous process – we are so grateful to the independent experts, Shape Network members and our SAC for their commitment in helping us to decide on the best research projects to fund. We can't wait to see the results from these studies and hear more from the promising researchers.

Annee Amjad
Head of Research & Involvement

Our 2024 Research Awards



Cognition in people with epilepsy and their offspring: How does epilepsy and its treatment affect brain function?

Epilepsy Research Institute North West Doctoral Training Centre, University of Liverpool and University of Manchester, awarded £287,558

Led by Dr Rebecca Bromley and Professor Simon Keller, the programme will train seven PhD students in epilepsy research, creating more epilepsy researchers of the future. The centre will explore cognition in people with epilepsy and their children. The results from these projects will help us to understand the disruption that epilepsy and anti-seizure medications cause to cognitive processes. The findings will also improve clinical practice by providing evidence-based decision-making and counselling tools for cognition in epilepsy.

"Epilepsy is more than just seizures. People with epilepsy often experience challenges with cognition and despite its importance, research on this topic has been largely overlooked. Our Doctoral Training Centre, split across the Universities of Manchester and Liverpool in partnership with local NHS Trusts, will combine world-leading expertise in pre-clinical and clinical brain research in order to answer these important questions."
Dr Rebecca Bromley



Reprogramming of reactive glia into fast-spiking interneurons in a mouse model of mesial temporal lobe epilepsy

Emerging Leader Fellowship – Dr Nicolas Marichal Negrin, King's College London, awarded £299,862

The team at King's College London have been converting glial cells in the brain into interneurons in a mouse model of temporal lobe epilepsy. Building on these promising results, this project aims to improve the conversion of glia into interneurons using a new 'recipe'. The team will try to create the exact kind of cells that have been lost in temporal lobe epilepsy and see how effective the new cells are at restoring the balance of electrical activity in the brain.

This research will advance this cell-reprogramming technique and explore whether replacing the lost interneurons could be a potential future treatment for temporal lobe epilepsy. The team hope that this technology could be tested in clinical trials and become a treatment for epilepsy.

"This project will further advance a novel cell-based therapeutic strategy to stop seizures in a common form of focal epilepsy, providing solid grounds for expanding its application to other forms of epilepsy."
Dr Nicolas Marichal Negrin



An international study to investigate and optimise the safety of discontinuing valproate in young men and women with epilepsy

Emerging Leader Fellowship – Dr Gashirai Mbizvo, University of Liverpool, awarded £299,996

This study will use anonymised research data that has already been collected from over 20,000 people with epilepsy who took valproate between 2015 and 2018. The team will compare people who discontinued valproate and started taking lamotrigine, levetiracetam or no new medication. They will look to see which of these groups had the highest rates of death, hospital admission, seizures, falls, poor mental health and other outcomes. This comparison will create a statistical personalised tool that can be used to predict which replacement anti-seizure medications are associated with the lowest risks.

"This study will benefit people living with epilepsy as a substantial number of young men and women may soon be invited by their doctor to consider coming off their valproate owing to concerns about the harm it may cause to their unborn child in future. Whilst this is an important risk to consider, these young men and women are likely to also ask what the risks of stopping the valproate are for their own health. This study will provide immediate evidence to help doctors answer that question. It will also empower the young men and women with a tool to help them select the safest alternative anti-seizure medication to replace the valproate."
Dr Gashirai Mbizvo



NETWORKS – Neuroscience-based Epilepsy Treatment With Optimised Retrospective Knowledge and Subcortical disconnection

Emerging Leader Fellowship – Mr Davide Giampiccolo, University College London, awarded £249,694

Davide's project will look at state-of-the-art brain imaging and clinical data collected over the last 15 years from over 1,000 people who've had surgery to treat epilepsy. The team will use this information to identify which brain pathways are important for stopping seizures. They will then use machine learning to analyse the connections that should be targeted for patients to become seizure free after surgery. The second stage of this project will build on the findings to offer participants this disconnection surgery, as an alternative to traditional epilepsy surgery, to see if they have a greater chance of long-term freedom from seizures.

"A third of individuals with epilepsy are resistant to medication, for whom surgery is the only possible cure. However, only half of patients become seizure free using current surgical techniques. There is increasing evidence that the brain's pathways are as involved in seizures as its surface, the cortex, so disconnecting these may support seizure freedom. With this project, we aim to evaluate which connections are the most important targets for surgery to enable seizure freedom, to help those patients for whom there is no other cure."
Mr Davide Giampiccolo

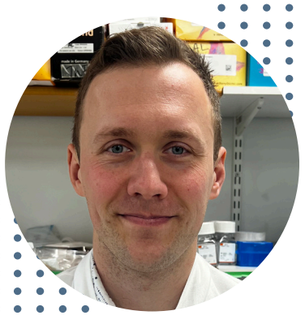


Development of a breath test for the diagnosis of epilepsy and the prediction of seizures

Emerging Leader Fellowship – Dr Ilaria Belluomo, Imperial College London, awarded £289,577

This project will collect breath and skin samples from people with different types of seizures, as well as from people who do not have seizures. The team will analyse these samples and look for a difference in molecule levels in people with and without seizures. They will also identify any molecules that change in level after a seizure, as these could be used to design a test to predict seizures. In the future, the team hope to develop these tests into a portable device which could be used both to diagnose epilepsy and to predict when someone might have a seizure.

"An accurate diagnosis of epilepsy and prediction of seizure onset can enormously improve quality of life of people with epilepsy. What these two problems have in common is the lack of non-invasive tests possible to perform before, during and after seizure. For this reason, non-invasive tests targeting volatile molecules emitted in breath and by skin can be a revolutionary tool in clinical epilepsy."
Dr Ilaria Belluomo



Investigating chromatin misfolding as a pathogenic mechanism in neurodevelopmental disorders

Epilepsy Research Institute & MRC Clinical Research Training Fellowship – Dr Oliver Davis University of Cambridge, awarded £270,458

DNA in our cells must be folded and stored correctly to give instructions to the cell and allow it to function properly. If not folded and stored properly, the DNA may not be able to instruct the cell about whether it should be stimulating or inhibiting electrical activity. This could be one of the reasons why people with epilepsy have too many stimulating cells and not enough inhibiting cells.

This study will investigate two genes that control DNA folding (called *FOXG1* and *CHD2*). Using cells in a dish to model a brain, the team will investigate what impact turning off these genes has on DNA folding and if this influences the number of cells that inhibit electrical activity.

"The findings of this study could have strong scientific and medical implications for epilepsy. We will provide some much-needed insight into how genes with DNA-folding functions control how our brains develop. This will be important medically, as it opens up the possibility that DNA misfolding is a mechanism for how some forms of epilepsy arise. Critically, this will provide new targets for scientists to design diagnostic tests or drugs for treatments, which could really help to improve the care for patients with hard-to-treat forms of epilepsy."
Dr Oliver Davis



Advancing precision medicine: genome engineering for on-demand gene therapy in Dravet syndrome

Epilepsy Research Institute & Dravet Syndrome UK Emerging Leader Fellowship – Dr Jenna Carpenter, University College London, awarded £222,752

Dravet Syndrome can cause frequent, treatment-resistant seizures as well as delayed development, intellectual disability and other comorbidities. More than 85% of people with Dravet Syndrome have a change in a gene known as *SCN1A*. This project will use a gene-editing technique to 'search and replace' the DNA sequences that control how the *SCN1A* gene is read. They hope this will activate the healthy *SCN1A* gene as and when it is needed by cells, which would overcome the disadvantages with current genetic therapies. The team will test this cutting-edge technology in human cells and 'mini brains' to see how well these sequences can treat Dravet Syndrome.

"I am thrilled to have the opportunity to develop a ground-breaking treatment for Dravet Syndrome. This innovative therapy offers a permanent cure, uniquely designed to adapt dynamically to the patient's developing brain over their lifetime. Beyond curing seizures, it promises to significantly alleviate other debilitating aspects of the disease. By integrating cutting-edge technologies in our research, we are setting a new standard of treatments for Dravet Syndrome and other rare genetic epilepsies."
Dr Jenna Carpenter



Understanding autonomic dysfunction in Dravet syndrome

Epilepsy Research Institute & Dravet Syndrome UK Emerging Leader Fellowship – Dr Lisa Clayton, University College London awarded £196, 863

People with Dravet Syndrome often experience dysautonomia – an abnormality in the way the body regulates internal organs and bodily processes such as heart rate, body temperature and digestion. This study will use autonomic function testing in people with Dravet Syndrome to learn more about dysautonomia and how it affects people. These simple tests can tell us if dysautonomia is present, how severe it is and its effects on different body systems. This study will help develop effective methods for screening for dysautonomia in people with Dravet Syndrome, predict who may develop it, and importantly try and find ways to prevent, limit or alleviate problems related to dysautonomia.

"Working closely with people living with Dravet Syndrome has deepened my understanding of the importance of non-seizure aspects of the condition, known as comorbidities. These comorbidities can negatively affect a person's overall health and have substantial impacts on the quality of life for those with Dravet Syndrome and their families. Dysautonomia is an important comorbidity in Dravet Syndrome which is poorly understood, but which may contribute to risks of seizures and sudden unexpected death in epilepsy through various mechanisms. Through my research, I hope to advance our understanding of dysautonomia in Dravet Syndrome, leading to better recognition, evaluation and management of this crucial comorbidity."
Dr Lisa Clayton

WHAT WE DID TO **DEVELOP RESEARCH PARTNERSHIPS AND COLLABORATIONS**

We mention it time and time again but epilepsy is far too complex a condition for any one organisation. To deliver all the breakthroughs the epilepsy community needs, we must develop partnerships and collaborations between academia, the NHS, industry, funders, patient groups, other charities and people affected by epilepsy. This year we focused on building new partnerships to unite them behind our goal of radically advancing epilepsy research.

Co-funded Fellowships with Dravet Syndrome UK

The Epilepsy Research Institute is co-funding two Fellowship projects with Dravet Syndrome UK (DSUK) to develop future leaders investigating Dravet Syndrome and epilepsy.

Dravet Syndrome is a rare neurological condition that affects around one in every 15,000 people in the UK. The condition encompasses treatment-resistant epilepsy, intellectual disability and a spectrum of associated conditions, which may include autism, ADHD and behaviours that challenge and difficulties with speech, mobility, eating and sleep. Read more about these projects on page 29.

Partnering with the MRC to fund a Clinical Research Training Fellowship

The Epilepsy Research Institute partnered with the Medical Research Council (MRC) to co-fund a Clinical Research Training Fellowship (CRTF). We were delighted to award the funding to Dr Oliver Davis from the University of Cambridge, who is investigating if DNA misfolding can cause neurodevelopmental disorders, such as epilepsy. Read more about this project on page 28.

Partner Organisation for the BNA's Festival of Neuroscience

In April 2023, the British Neuroscience Association (BNA) hosted its fifth Festival of Neuroscience in Brighton, welcoming neuroscientists and researchers from across the UK and beyond. The Epilepsy Research Institute is a proud Partner Organisation of the BNA and hosted the conference's only epilepsy-focused symposium, championing the work of early career researchers across epilepsy.



Founding Partners

Epilepsy Action, Young Epilepsy, Epilepsy Scotland and the ILAE (British Branch) have all played an active role in the initiation of the Epilepsy Research Institute and each has a seat on our Board of Trustees. The role of each Founding Partner is key to us placing collaborative working at the centre of the governance of the Institute.

The Founding Partners contribute to the strategic direction of the Institute and ensure the Institute takes a holistic approach to the experiences of people affected by epilepsy. This year, we held a research reception with Founding Partner Young Epilepsy, which brought together charities, funders, people affected by epilepsy, researchers and other epilepsy research stakeholders and united them in our efforts to radically advance research into epilepsy. We have also begun planning a joint roundtable event with Epilepsy Scotland for the Autumn of 2024.

Research Roundtable with the UK Dementia Research Institute

Epilepsy often co-occurs with other conditions, so by partnering with disease-specific charities, it can help to reveal new insights by sharing our expertise from different areas. It also avoids duplicating efforts and makes the most of our research funding.

In January 2024, the Epilepsy Research Institute hosted a Research Roundtable with the UK Dementia Research Institute at our head office in London. Researchers have found strong links between the two conditions and their underlying mechanisms, including the potential of using anti-seizure medications to treat dementia, which is currently being investigated. This is important as more and more people are being diagnosed with epilepsy at an older age.

The event brought together 20 leading researchers working in the fields of epilepsy and dementia to identify opportunities to advance much-needed collaborative research in this area. Bringing researchers together and strengthening networks enables the sharing of vital knowledge across conditions and of overlapping research methodologies. By facilitating this, we hope to enable new multidisciplinary collaborations, foster research partnerships and drive much needed strategic investment.



"People with Alzheimer's disease often experience seizures and, at the same time, people with epilepsy experience cognitive impairment and cognitive decline. Today, we brought together researchers working in both fields to explore this borderline between the two conditions. Lots of synergies and commonalities were identified which can be explored further, to hopefully make real progress in understanding the overlap and develop better therapies."
Dr Marc Busche
UK DRI Group Leader at University College London, Roundtable Co-chair

WHAT WE DID TO **ADVOCATE & ACTION RESEARCH PRIORITIES OF PEOPLE AFFECTED BY EPILEPSY**

Central to the work of the Epilepsy Research Institute is a culture of advocating and actioning our research priorities and involving people affected by epilepsy through our Patient and Public Involvement and Engagement (PPIE) activities. Informed by the UK Epilepsy Priority Setting Partnership (PSP) Top Ten priorities, our research strategy focuses on six key themes that will make the biggest difference to people affected by epilepsy.

Shape Network

Our Shape Network is now the largest PPIE group focused on epilepsy with over 500 members, all of whom are affected by the condition. The network enables researchers to make studies more effective, relevant and cost-effective. It also means we can ensure research is focused on the most important outcomes for people living with epilepsy.

Members of the Shape Network work in partnership with researchers to plan, design, manage, evaluate and disseminate research. All research funded through our grant round has involved people living with and affected by epilepsy through our Shape Network Application Clinics, which enable participants to discuss and debate research grant proposals with the researchers developing them.



"Members of the Shape Network provided extremely valuable insights. During the discussion we explored future objectives, potential side effects, and the feasibility of implementing the treatment in both drug-resistant and drug-responsive epilepsy models. These very important insights are now included in my final application. The clinic was a huge source of motivation – I am determined to make this project a success for people affected by epilepsy."
Nicolas Marichal Negrin, *2024 Emerging Leader Fellow*

EpiSafe Project

The National Institute for Health and Care Research (NIHR) has invested over £2.7 million in research aiming to reduce maternal mortality risk and improve the care of pregnant women with epilepsy. Led by researchers at the University of Birmingham in collaboration with the Epilepsy Research Institute Shape Network, the EpiSafe project was launched in November 2023 at an event hosted by Baroness Cumberlege at the House of Lords.

This project will trial an evidence-based, personalised care programme specifically designed for pregnant women with epilepsy. The Institute's Director of Research Operations, Dr Caoimhe Twohig-Bennett, said: " We are delighted to be collaborating on the EpiSafe project, to ensure safer care and reduced risks for pregnant women with epilepsy.

"Central to the work of the Institute is a culture of advocating and actioning the research priorities of people affected by epilepsy through our Shape Network PPIE group. Members of the network have been pivotal in the development of this programme of research, and we look forward to their continued involvement as this important project progresses."



VIEWPOINT

Lisa is living with a form of epilepsy called transient epileptic amnesia (TEA). In 2023, Lisa signed up to be part of the Shape Network and has since joined a number of panels to review grant applications. Lisa shares her motivation for getting involved.

My epilepsy journey began when my husband would find me staring blankly into space and then I'd briefly not know who people were or where I was. I was also forgetting things, both recent and from my past. I didn't believe there was anything wrong for a long time. I finally saw my doctor and was referred to a consultant who told me it was likely to be epilepsy; a kind called transient epileptic amnesia (TEA). I was completely shocked. I had no family history of epilepsy and didn't know much about it.

My seizures were short periods of absence and confusion. I also had big gaps in my memory including most holidays and many family events. I couldn't concentrate, forgot things, and got tired easily. I felt lost every time I went out as I didn't know where to go or the way back; places I used to know were strange to me.

I had to stop driving and to withdraw from a job application. I lost a lot of confidence. After starting medication, the seizures stopped and after a while I felt more like my old self. I still experience some of the problems and the missing memories of my life haven't come back, but things are getting better. I'm grateful that I was diagnosed so quickly and for the support of my family and friends.

Research is vital to improve treatments and improve the lives of people affected by epilepsy. It's important that the research being done takes into account the views of people who have epilepsy or care for someone who does. I found out about the Epilepsy Research Institute's Shape Network on its website in early 2023 and signed up.

"I wanted to be a part of something relevant to me and that was at the sharp end of changing things."

When the opportunity to be involved as a layperson in the Institute's grant round applications came up, I put myself forward.

I was part of several panels looking at grant applications, written in ordinary language, and talking to the researchers to make sure they were listening to the people directly involved and would communicate about their research in a straightforward way. Being part of a study or talking to the scientists doing the research means using your experience to help make the studies more effective.

Epilepsy has particularly affected my memory, both long and short term. Memory loss affects many other people with epilepsy as well, so I hope that more research is done in this area. I was pleased to see that impact on brain health, including memory loss, was a Top Ten epilepsy research priority and will be a focus of the Institute's Neurodevelopment research theme.

My hope is that research will lead to better treatments and understanding, meaning that in the future living with epilepsy will be easier.

Lisa
Shape Network member



OUR RESEARCH IMPACT AND **PERFORMANCE**

Membership of the Association of Medical Research Charities (AMRC) is the hallmark of quality and credibility. It means we fund high-quality research associated with a published research strategy, a robust peer-review process and a comprehensive conflicts of interest policy.

As members, our research procedures are audited every five years to ensure they meet the AMRC's exacting membership standards. For universities, government and funding bodies, AMRC membership is the recognised indicator of quality. We also attend regular training alongside other research charities to develop best practice approaches and share learning.

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 continuing to assess the level of funding they subsequently secure from other funders to progress the work.

In the last five years, we have invested over £6.9 million on research grants and these have leveraged over £37.8 million in follow-on funding from other sources. Therefore, every pound invested by the Epilepsy Research Institute has generated a further £5.41 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 460 journal publications have resulted from our awarded grants during the 2009–2024 period, 106 of which were in high impact journals (impact factor of 10 or above) such as *Brain*, *Nature* and *Science*. Further evidence of the quality of the work we fund is the number of citations these publications have achieved (i.e. the number of times the publications have been referred to by other researchers in their own work). In this case, our publications have been cited over 4,500 times.

In this section, we interview two researchers who have recently finished successful projects and gone on to secure further funding.



FINAL REPORT: UNDERSTANDING AND TREATING *DNM1* EPILEPSY

In 2020, the Epilepsy Research Institute awarded an Endeavour Project Grant to Professor Mike Cousin and his team at the University of Edinburgh. The team has been investigating if dysfunctional endocytosis can result in *DNM1* epilepsy, and whether existing drugs could correct faulty endocytosis and be used to treat epilepsy. Since the project ended in December 2023, Professor Cousin has gone on to secure a further £1.04m in follow-on-funding from the Medical Research Council (MRC).

What is *DNM1* epilepsy?

Epileptic encephalopathies (EEs) are a group of severe epilepsies where seizure activity overrides the normal function of the brain. This is often caused by genetic mutations and can result in drug-resistant epilepsy. One specific type of EE is caused by mutations in the gene *DNM1* (*DNM1* EEs) which is involved in a brain communication process called endocytosis.

What were the findings from this project?

To test our hypotheses, we generated a mouse model that carried the most common human *DNM1* mutation to replicate *DNM1* EE. As predicted, we found that brain cells from this model displayed a specific defect in endocytosis. In addition, the model displayed defects in brain communication that result in overexcitability, as well as seizure-like behaviour. Therefore, the mouse model was a robust and accurate model of *DNM1* EE in which to test new drugs.

An existing drug was identified which accelerated endocytosis in unaffected brain cells. We believed that owing to these properties, the drug could also correct the epilepsy characteristics in our mouse model. This turned out to be the case, with the drug correcting dysfunction in: 1) endocytosis; 2) brain excitability; and 3) seizure-like behaviour. Importantly, this drug also corrected endocytosis in cells that had different *DNM1* mutants, suggesting it could be used for other types of EE.

What does this mean for people affected by epilepsy?

By identifying that dysfunctional endocytosis is causal in EEs, endocytosis itself can be targeted, in addition to the affected gene. For people with genetic epilepsies, this provides a new avenue for potential therapeutic interventions.

This includes the drug we identified in the project which could be rapidly translated to clinical trials of *DNM1* EE and other epilepsies, as well as further existing drugs yet to be identified.

Now the project has finished, what's next?

Since this project has finished, I have been able to secure a further £1.04m in funding from the MRC. In this follow-on project, we will be investigating how the drug we identified works and whether it has wider therapeutic potential. We will also be using gene therapy techniques to determine whether the removal of the *DNM1* gene could effectively treat epilepsy.



FINAL REPORT: EXPLORING A PROMISING NEW DRUG TARGET TO STOP SEIZURES IN THEIR TRACKS

Dr Vincent Magloire's previous research has led to the identification of a promising new candidate for restoring inhibition: the neurogliaform (NGF) interneuron. These inhibitory brain cells are located across the entire surface of the brain and exert particularly powerful and long-lasting inhibitory control over other neurons. In 2019, Dr Magloire was awarded an Emerging Leadership Fellowship to further this work. The project aimed to manipulate NGF interneuron activity and thereby their inhibitory power in order to stop focal and generalised seizures.

Why are neurogliaform cells important in epilepsy?

Seizures arise from a failure of the brain inhibitory system to restrain excitation. An attractive therapeutic approach consists of rescuing this system by genetically manipulating specific populations of brain cells. The neurogliaform (NGF) cell, which is uniquely positioned to exert powerful, widespread and long-lasting inhibitory control over brain excitation, is a highly promising candidate cell type. My Fellowship project aimed to test whether this unusually strong inhibition can be harnessed to rescue epilepsy.

What did your project find?

We have now confirmed that NGF cell activation has a strong and persistent anti-epileptic effect in models of epilepsy. Using two different complementary methods, we showed that this strategy significantly reduced the frequency of interictal spikes as well as the duration of seizures. Importantly, this is the first evidence that NGF cells can be harnessed to reduce seizure activity. Thanks to these promising findings, we are now testing whether NGF cell activation can prevent seizures in a model of chronic epilepsy, which will recapitulate the aetiology of temporal lobe epilepsy. It is an important step towards understanding whether this approach can be translatable. In addition, we have made progress on optimising the best strategy to recruit NGF cells across a wide area of the cortex. However, more time and resources are necessary to further develop this strategy.

Understanding whether NGF cell activation can be a viable therapeutical approach is of significant importance in relation to tailoring future gene therapies for refractory epilepsy, while also minimising potential side effects.

Why was this Fellowship funding important?

I am very grateful to have been awarded this Fellowship. It has allowed me to obtain my first independent position within the Department of Clinical and Experimental Epilepsy at University College London, and to start my research group on epilepsy. In addition, it strongly contributed to securing a permanent position at University Claude Bernand Lyon, as well as further grant funding totalling over £3 million. I have very much enjoyed working with the Institute, and I am very grateful for their support throughout all those years, particularly through the pandemic.

OUR SUPPORTER **HIGHLIGHTS**

Thank you to our amazing fundraisers, supporters and volunteers. Your commitment and determination to help us achieve a life free from epilepsy is what makes breakthroughs possible.

To everyone who bakes, runs, swims, volunteers, donates or has left a gift in their will – your efforts are felt in hospitals, labs and universities across the UK. The record-breaking research funding and the establishment of the Epilepsy Research Institute has only been possible because of your achievements. Thank you.



TOGETHER WE WILL RADICALLY ADVANCE **RESEARCH INTO EPILEPSY**

London Marathon 2023

Thank you so much to our marathon superstars for all their hard work and dedication. Together, they raised an incredible £14,700 for vital research into epilepsy. The team knows only too well how epilepsy interrupts lives, but also that through research we can achieve a life free from epilepsy.







"Running the London Marathon has been a goal for me for years and it was everything I had hoped for and more! I loved every minute – the crowds and support were amazing. It exceeded all expectations and I also surpassed my fundraising target to help people impacted by epilepsy. The prosecco at the end has never tasted better!"
Anna

Great North Run 2023

Over 40 incredible runners took to the Newcastle streets, running 13.1 miles in aid of epilepsy research. For Sarah, it was her sixth Great North Run; "The Great North Run is such a fantastic event and being able to support the Epilepsy Research Institute was a privilege. We hope the money raised will allow further vital research into epilepsy to take place. We look forward to doing it again next year!"





Cycling (over 300km) for research

Led by Theo, Macquarie Asset Management took on a mammoth two-day London to Paris cycle challenge (over 300km!), raising over £50,000. Theo said, "This year will mark the 15th anniversary of the operation that changed my life and cured me from epilepsy. We hope to raise awareness about epilepsy and support Epilepsy Research Institute in its efforts to improve the lives of those affected by the condition."





Long-term supporters Farnell achieve huge milestone

Two decades ago, the former CEO of electronics company Premier Farnell tragically lost his son to SUDEP at just 21 years old. The Farnell community responded with incredible compassion and support, which has continued through fundraising and awareness events for over 20 years. With this year's annual golf day, they surpassed the remarkable milestone of £200k total raised.

















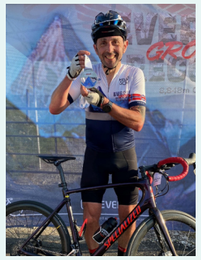


























TRUSTEES' REPORT AND **FINANCIAL STATEMENTS**

YEAR ENDING 31 MARCH 2024

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 31 March 2024, 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 2019).

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 PhD FRCP (Chair)
Mr Barrie Akin LLB FCA
Mr Joseph Brice BA (Hons) (Resigned November 2023)
Professor Michael Cousin BSc PhD
Dr Anne Coxon DPsych
Mr Mark Devlin BSc MSc (Appointed December 2023)
Professor Martin Elliot MB BS MD FRCS
Dr Abbie Fearon-Yorke PhD (Appointed September 2023)
Professor Anthony Marson MB ChB MD, FRCP FEAN
Professor Nicholas Lench BSc PhD FRCPath
Professor Mark Richardson MA BMBCh MRCP PhD CCST FRCP
Professor Stephanie Schorge BSc PhD SFHEA (resigned September 2023)
Ms Rebekah Smith BA (Hons) DipM ACIM CMgr FCMI. (Appointed December 2023)
Ms Juliet Solomon (Appointed December 2023)
Miss Judith Spencer-Gregson MSc FCA
Dr Rhys Thomas BSc MSc PhD MBChB MRCP
Dr Sukhvir Wright BSc PhD MBBS
Mrs Lesslie Young OBE (Appointed December 2023)

President

Professor J Helen Cross OBE MB ChB PhD FRCP(UK) FRCPCH

Chief Executive

Ms Rosemarie Pardington BSc (Hons) MBA Ad DipPR DipM DipSS MCIM MIQA (Appointed 29 January 2024)
Ms Maxine Smeaton MSc PGDip MInstF (Resigned 29 February 2024)

Independent auditors

Kreston Reeves, Springfield House, Springfield Road, Horsham, West Sussex, RH12 2RG

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

Withers LLP. 20 Old Bailey, London EC4M 7AN
BDB Pitmans LLP, One Bartholomew Close, London EC1A 7BL

Registered:

Charity number 1100394
Company number 4873718

Head Office

Churchill House
35 Red Lion Square
London WC1R 4SG

Previously (until 20 September 2023):
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 a growing programme of research, encouraging collaboration amongst researchers and raising awareness of the need for more funding for epilepsy research.

An outline of key activities to meet these objectives are provided in the earlier sections of the annual report principally around the funding of research grants, the development of research programmes and advocating the priorities of people affected by epilepsy. Our future plans are highlighted throughout, particularly in the description of our research ambitions. The impact section of the report details significant achievements across our work.

Financial Review

In 2023-24 overall incoming resources were £3,595,109 which was very similar to our income in the previous year of £3,605,370.

The costs of raising funds were £177,658 (2023 £173,303) but we increased our expenditure on charitable activities by 17% to £2,913,605 (2023: £2,485,123)

This year we were fortunate in receiving a further grant of £1,478,851 (2023 £1,451,840) from the government's Medical Research Charities Early-Career Researcher Fund to compensate for delays to research for early career researchers. We also had levels of legacy income higher than anticipated which has enabled more funds to be transferred to the designated research fund to be utilised over subsequent years to deliver the development of the research strategy.

2023-24 saw a record level of grants awarded - £2,028,835 (2023: £1,758,950) giving a total amount of grants committed to £6,314,802 (2023: £5,609,511). Bank balances of £2,197,361 (2023: £3,557,081) are held for ongoing grant commitments and day to day liabilities.

Specific investment powers of the trustees

The trustees, having regard to the liquidity requirements of research grants awarded, have invested funds in medium and long term investments and also hold an amount of treasury cash. Income from investments performed well and there was an unrealised gain on investment value in the year of £278,842 (2023: (loss) -£263,090).

Going Concern

The trustees are confident that the new Epilepsy Research Institute will enable us to seek strategic investment from institutional funders and widen our funding sources.

The balance sheet shows net assets of £4,178,272 (2023: £3,395,584) and as such the Trustees consider the charity to be a going concern.

The reserves policy has therefore proved to be adequate to enable Epilepsy Research Institute to meet its commitments, without any adverse impact on our research activities.

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, based on the financial impact of the current risks facing the charity, and is formally reviewed each year 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.

Designated reserves are held to enable the charity to focus on awarding a sustainable level of research grants supporting the strategic priorities of the charity.

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 2024 are £3,278,272 (2023: £2,494,171) which will enable the charity to focus on a sustainable level of research grants supporting the new strategy.

Fundraising approach and performance in 2023-24

The overall incoming resources from donations and legacies during 2023-24 were £1,886,154 a decrease in income of 4% compared to the previous year (£1,967,065). Legacy income in the year was £997,334 (2023 £928,728) and we are always humbled by the generosity of those who remember us in their wills. Last year, 24% of our funding came from our community of supporters. We greatly appreciate and recognise the importance and value of the relationship with our supporters. We ensure they are kept informed and inspired by the way the organisation both raises and spends its funds. We are mindful of the impact the cost-of-living crisis will have on our supporters. We will ensure 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. 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.

Structure, governance and management

Governing document

The Epilepsy Research Institute UK is a charitable company limited by guarantee, incorporated (as Epilepsy Research Foundation) on 21 August 2003 and registered as a charity on 30 October 2003. The company is governed by its Memorandum and Articles of Association.

On 22 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 30 March 2007. In the event of the company being wound up members are required to contribute an amount not exceeding £1. Members of the organisation are the original signatories to the Memorandum and Articles of Association, current and past trustees and those specifically invited to serve as members.

On 8 June 2023, the name of the organisation was amended from Epilepsy Research UK to Epilepsy Research Institute UK following a special resolution passed on 15 May 2023.

During the coming financial year 2024-25, the Articles of Association will be fully revised to take account of Institute status.

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 Institute UK as the sole member. Confirmation statements and dormant company accounts are submitted for these two entities to Companies House on an annual basis.

Organisation

The activities of the Epilepsy Research Institute UK are governed by the Board of Trustees, all of whom are Directors. The Board meets at least four times per year. There are three key subcommittees; the Nominations Committee and the Finance & Audit subcommittee and the Scientific Advisory Committee.

The Chief Executive is appointed by the trustees to manage the day-to-day operations of the charity.

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.

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. Under the current Articles, at each Annual General Meeting one third of the trustees must retire and, if required, 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. After consideration by the Nominations and Advisory Committee, these individuals are proposed to the Board of Trustees at subsequent AGMs ratified by the full membership of the organisation. This process will be revised as part of the revision of the Articles of Association during 2024-25.

Founding Partner trustees

Crucial to the establishment of the Institute, a number of Founding Partner organisations were put at the heart of its strategic development to ensure the whole epilepsy community could drive the collective research agenda.

This included:

- Epilepsy Action
- Epilepsy Scotland
- International League Against Epilepsy (British Branch)
- Young Epilepsy

Founding Partner status has initially been dictated by a Memorandum of Understanding (MoU) which outlines the scope of membership and defines terms of engagement.

As part of the MoU, each partner organisation nominated a senior individual to sit on the Board of Trustees. These were appointed in December 2023. The MoU will be reviewed as part of the revision of the Institute's Articles of Association in 2024-25.

Trustee induction and training

All new trustees receive a copy of the Charity Commission publication The Essential Trustee. In March 2024 we ran an induction session for all recently appointed trustees. The induction process for trustees will be reviewed during 2024-25.

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 11 to the accounts. The Nominations Committee review employee pay on an annual basis (excluding the Chief Executive) 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.

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 has focused on risks associated with delivering our strategy and the 2023-24 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. The 2023-24 risk plan was approved at the Board of Trustees meeting in March 2023.

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 fundraising)
3. Strategic partnership work.

Key areas of identified risk for 2023-24 were those associated with:

- Fundraising strategy and in particular risks to legacy funding.
- The Institute failing to meet its aspirations.

The Board of Trustees are satisfied that the major risks have been identified and processes for mitigating them are in place. A number of policies and procedures have been developed to support this. 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 regular basis.

Statement of trustees' responsibilities

The charity trustees (who are also the directors of Epilepsy Research Institute 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

Signed on behalf of the Board of Trustees on 1 October 2024

REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES **OF THE EPILEPSY RESEARCH INSTITUTE**

Opinion on financial statements

We have audited the financial statements of the Epilepsy Research Institute UK ("the charitable company") for the year ended 31 March 2024 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement including changes in net debt and notes to the financial statements, including a 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).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2024, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis 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 charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

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

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

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

Other information

The other information comprises the information included in the Trustees' Annual Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the Annual Report. 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. 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 course of 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 this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

- the information given in the Trustees' Annual Report (incorporating the Strategic Report and the Directors' Report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Strategic Report and the Directors' Report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Strategic Report included within the Trustees' report.

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

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of directors' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

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

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conduct in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatement can arise from fraud or error and are consider 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.

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

Capability of the audit in detecting irregularities, including fraud

Based on our understanding of the Charity, and through discussion with the directors and other management (as required by auditing standards), we identified that the principal risks of non-compliance with laws and regulations related to GDPR and employment law. We considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006. We communicated identified laws and regulations throughout our team and remained alert to any indications of non-compliance throughout the audit. We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to posting inappropriate journal entries to increase revenue or reduce expenditure, the recognition of grants payable and revenue recognition.

Audit procedures performed by the engagement team included:

- Discussions with management and assessment of known or suspected instances of non-compliance with laws and regulations and fraud, and review of the reports made by management; and
- Assessment of identified fraud risk factors; and
- Holding discussions with appropriate personnel to gain further insight into the control systems implemented, and the risk of irregularity; and
- Performing analytical procedures to identify any unusual or unexpected relationships, including related party transactions, that may indicate risks of material misstatement due to fraud; and
- Confirmation of related parties with management, and review of transactions throughout the period to identify any previously undisclosed transactions with related parties outside the normal course of business; and
- Reading minutes of meetings of those charged with governance and reviewing correspondence with relevant tax and regulatory authorities; and
- Verifying the year-end cash at bank balances to online banking portals to verify accuracy; and
- Review of significant and unusual transactions and evaluation of the underlying financial rationale supporting the transactions; and
- Identifying and testing journal entries, in particular any manual entries made at the year end for financial statement preparation.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment 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 charitable company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation (ie. gives a true and fair view).

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

Use of our report

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

James Peach BA FCA (Senior Statutory Auditor)
For and on behalf of Kreston Reeves LLP
Chartered Accountants and Statutory Auditor
Horsham
Date:

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2024

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £	Total Funds 2023 £
Income from:					
Donations and legacies	2	1,816,004	70,150	**1,886,154**	1,967,065
Grants	3	-	1,478,851	**1,478,851**	1,451,840
Other trading activities	4	3,608	-	**3,608**	18,193
Investments	5	226,496	-	**226,496**	168,272
Total Income		2,046,108	1,549,001	**3,595,109**	3,605,370
Expenditure on:					
Cost of raising funds					
Raising Funds	6	177,658	-	177,658	173,303
Charitable activities					
Research grants committed	7	1,999,070	-	**1,999,070**	1,705,986
Other research activities	8	870,782	43,753	**914,535**	779,137
Total charitable expenditure		2,869,852	43,753	**2,913,605**	2,485,123
Total expenditure		3,047,510	43,753	**3,091,263**	2,658,426
Net unrealised gains / (losses) on investments		278,842	-	**278,842**	(263,090)
Net income/(expenditure) for the year		(722,560)	1,505,248	**782,688**	683,854
Transfers between funds	15	1,506,661	(1,506,661)	-	-
Net movement in funds for the year		**784,101**	**(1,413)**	**782,688**	**683,854**
Reconciliation of funds:					
Total funds brought forward on 1 April		3,394,171	1,413	**3,395,584**	2,711,730
Total funds carried forward at 31 March	17	**4,178,272**	-	**4,178,272**	3,395,584

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 56 to 69 form part of these financial statements.

BALANCE SHEET
AS AT 31 MARCH 2024

	Note	2024 £	2023 £
Fixed assets			
Investments	12	**7,552,532**	3,740,842
		7,552,532	3,740,842
Current assets			
Debtors	13	**846,091**	1,868,069
Cash at bank and in hand		**2,197,361**	3,557,081
		3,043,452	5,425,150
Creditors: amounts falling due within one year	14	**(3,417,158)**	(2,926,568)
Net current (liabilities)/assets		**(373,706)**	2,498,582
Total assets less current liabilities		**7,178,826**	6,239,424
Creditors: amounts falling due within one year	14	**(3,000,554)**	(2,843,840)
Total net assets		**4,178,272**	3,395,584
The funds of the charity			
Unrestricted funds	15		
Designated funds		**3,278,272**	2,494,171
General fund		**900,000**	900,000
		4,178,272	3,394,171
Restricted funds	16	**-**	1,413
Total charity funds		**4,178,272**	**3,395,584**

The financial statements were approved by the Board of Trustees on 1 October 2024 and signed on its behalf by:

Prof Matthew Walker
Chair

Judith Spencer-Gregson FCA
Treasurer

Registered company number: 4873718
Registered charity number: 1100394

The notes on pages 56 to 69 form part of these financial statements.

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2024

	2024 £	2023 £
Cash inflow from operating activities	**1,946,632**	469,541
Cash flows from investing activities		
Sale of investments	**-**	-
Net purchase of investments	**(3,375,000)**	-
Income reinvested	**(157,845)**	(106,764)
Dividends and interest received	**226,493**	168,269
Net cash inflow/(outflow) from investing activities	**(3,306,352)**	61,505
Increase/(decrease) in cash and cash equivalents in the year	**(1,359,720)**	531,046
Cash and cash equivalents at the beginning of the year	**3,557,081**	3,026,035
Cash and cash equivalents at the end of the year	**2,197,361**	3,557,081

Reconciliation of net movement in funds to net cash flow from operating activities

Net movement in funds	**782,688**	683,854
Deduct investment income shown in investing activities	**(226,496)**	(168,272)
Deduct investment gain/add (loss)	**(278,842)**	263,090
(Increase)/decrease in debtors	**1,021,978**	(1,127,994)
Increase/ (decrease) in creditors due within one year	**490,590**	919,539
Increase/(decrease) in creditors due after more than one year	**156,714**	(100,676)
Net cash from/used in operating activities	**1,946,632**	**469,541**

Analysis of cash and cash equivalents

Cash deposits	**1,886,696**	2,852,508
Cash at bank	**310,665**	704,573
Net Cash from/used in operating activities	**2,197,361**	**3,577,081**

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

Analysis of changes in net debt	**As at 31 Mar 23**	**Cashflows**	**As at 31 Mar 24**
Cash deposits and cash at bank	**3,557,081**	**(1,359,720)**	**2,197,361**

There were no overdrafts, loans or finance lease obligations within the period

NOTES FORMING PART OF THE FINANCIAL STATEMENTS
FOR THE YEAR ENDING 31 MARCH 2024

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 2019) – 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 Institute 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 are covered by our cash balances, deposits and investments.

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) 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.

k) 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.

l) Leases
The charity entered in to a new operating lease in September 2023 for its new office space. Payments made under the lease agreement have been taken to expenditure. The balance of the remaining lease is not shown on the balance sheet but is shown in note 19.

2 DONATIONS AND LEGACIES

	Unrestricted Funds £	Restricted Funds £	Total 2024 £	Total 2023 £
Charitable trusts	36,664	70,000	106,664	209,090
In memoriam donations	81,591	-	81,591	87,519
Other donations	365,440	150	365,590	475,501
Fundraising events	334,975	-	334,975	266,227
Legacies	997,334	-	997,334	928,728
	1,816,004	70,150	1,886,154	1,967,065

Donations and Legacies 2023

	Unrestricted Funds £	Restricted Funds £	Total 2023 £
Charitable trusts	90,390	118,700	209,090
In memoriam donations	87,519	-	87,519
Other donations	293,546	181,955	475,501
Fundraising events	266,130	97	266,227
Legacies	928,728	-	928,728
	1,666,313	300,752	1,967,065

Income from fundraising events arises from events organised by the charity and its supporters.
Online advertising to the value of £66,393 (2023: £95,403) 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.

3 GRANTS RECEIVED

	Unrestricted Funds £	Restricted Funds £	Total 2024 £	Unrestricted Total 2023 £
UKRI - Medical Research Charity Support	-	1,478,851	1,478,851	-
BEIS COVID-19 charity support fund	-	-	-	1,451,840

4 OTHER TRADING ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	Total 2024 £	Unrestricted Total 2023 £
Sale of christmas cards	3,608	-	3,608	17,593
Fees charged	-	-	-	600
	3,608	-	3,608	18,193

5 INVESTMENT INCOME

	Unrestricted Funds £	Restricted Funds £	Total 2024 £	Unrestricted Total 2023 £
Dividend & investment income	120,389	-	120,389	150,461
Interest on deposits	106,107	-	106,107	17,808
	226,496	-	226,496	168,269

6 COSTS OF GENERATING FUNDS

	Unrestricted Funds £	Restricted Funds £	Total 2024 £	Unrestricted Total 2023 £
Direct fundraising	55,962	-	55,962	100,482
Staff costs	81,356	-	81,356	49,597
Other overhead expenses	24,992	-	24,992	11,026
Governance costs	15,348	-	15,348	12,198
	177,658	-	177,658	173,303

7 RESEARCH GRANTS COMMITTED

	2024 £	2023 £
Committed as at 31 March 2023	5,609,511	4,913,045
Authorised during year (see Trustees' report)	2,028,835	1,758,950
No longer required	(29,765)	(52,964)
Paid in year	(1,293,779)	(1,009,520)
Committed as at 31 March 2024	6,314,802	5,609,511

Authorised grants represent awards made to research institutions to further the understanding and treatment of epilepsy. An overview of the awards are set out in the Trustees report on pages 24-29. Details of all grants awarded are available on the website: epilepsy-institute.org.uk/eri/research/research-portfolio/. Grants no longer required relates to projects that were completed without the original grant being spent.

8 OTHER RESEARCH ACTIVITIES

	Unrestricted Funds £	Restricted Funds £	Total 2024 £	Total 2023 £
Staff costs	449,704	39,289	488,993	404,826
Director of National Epilepsy	32,795	-	32,795	12,889
Research meetings, events & activities	50,992	3,662	54,654	55,850
Research awards & prizes	-	500	500	500
Research dissemination & communication	99,435	-	99,435	115,528
Institute transition	28,365	-	28,365	-
Overhead expenses	129,692	302	129,994	89,989
Governance costs	79,799	-	79,799	99,555
	870,782	43,753	914,535	779,137

Other Research Activities 2023

	Unrestricted Funds £	Restricted Funds £	Total 2023 £
Staff costs	359,300	45,526	404,826
Director of National Epilepsy	12,889	-	12,889
Research meetings, events & activities	38,242	17,608	55,850
Research awards & prizes	-	500	500
Research dissemination & communication	115,528	-	115,528
Overhead expenses	80,099	9,890	89,989
Governance costs	99,555	-	99,555
	705,613	73,524	779,137

9 SUPPORT AND GOVERNANCE COSTS

	Support Costs £	Governance Costs £	Total 2024 £	Total 2023 £
Staff costs	-	31,336	31,336	34,712
Other staff costs	39,388	-	39,388	45,828
Office rent & facilities	49,675	-	49,675	22,376
Office running costs	29,676	-	29,676	13,341
IT & bank charges	36,247	-	36,247	27,191
Investment fees	-	25,623	25,623	39,197
Audit	-	16,200	16,200	15,986
Trustee meetings & expenses	-	12,325	12,325	6,950
Legal & professional fees	-	9,663	9,663	7,187
	154,986	95,147	250,133	212,768
Basis of allocation				
Allocated to fundraising costs	24,992	15,348	40,340	16.13%
Allocated to charitable activities	129,994	79,799	209,793	83.87%
	154,986	95,147	250,133	100.00%

Support and Governance costs 2023

		Support Costs £	Governance Costs £	Total 2023 £
Staff costs		-	34,712	34,712
Other staff costs		45,828	-	45,828
Office rent and facilities		22,376	-	22,376
Office running costs		13,341	-	13,341
IT and bank charges		27,191	-	27,191
Investment fees		-	39,197	39,197
Audit		-	15,986	15,986
Trustee meetings & expenses		-	6,950	6,950
Legal & professional fees		-	7,187	7,187
		108,736	104,032	212,768
Basis of allocation				
Allocated to fundraising costs	10.91%	11,868	11,355	23,223
Allocated to charitable activities	89.09%	96,868	92,677	189,545
	100.00%	108,736	104,032	212,768

10 TOTAL AUDITOR'S REMUNERATION

	2024 £	2023 £
Remuneration in relation to the audit of the finanical statements	16,200	15,986
Remuneration for other services: payroll processing	444	1,470

11 STAFF COSTS

	2024 £	2023 £
Salaries	524,683	418,781
Social security costs	53,180	42,098
Pension costs	23,822	28,257
	601,685	489,136

Employees receiving salaries within the following bands:

	2024	2023
£80,0001 to £90,000	1	1

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

	2024	2023
Charitable activities	7.80	8.29
Fundraising	1.60	0.98
Governance	0.60	0.78
	10.00	10.05

Epilepsy Research Institute UK incurred total Trustee and key management personnel remuneration costs during the period of £122,426 (2023: £100,278). The Trustees do not receive any remuneration for their duties and during the year received expenses of £6,311for travelling to meetings (2023: £1,999). 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.

12 INVESTMENTS

	2024 Liquidity Fund £	2024 Long & Medium Term Portfolio £	2024 TOTAL £	2023 Long & Medium Term Portfolio £
Market value 1 April 2023	0	3,740,842	3,740,842	3,897,165
Acquisitions	3,375,000	0	3,375,000	-
Sales at market value	0	0	0	-
Investment charges	(313)	(18,160)	(18,473)	(43,697)
Income reinvested	55,932	120,386	176,318	150,461
	3,430,619	3,843,068	7,273,687	4,003,929
Net gain/(loss) realised	3	0	3	3
Net gain/(loss) unrealised	0	278,842	278,842	(263,090)
Market value 31 March 2024	3,430,622	4,121,910	7,552,532	3,740,842

Analysis of investments:

	2024 £	2023 £
Quoted Charity Common Investment funds		
Medium and long term	4,116,391	3,617,408
Liquidity fund	3,430,622	-
Cash on deposit	5,519	123,434
	7,552,532	3,740,842

During the year the Trustees transferred additional cash from bank accounts to a liquidty fund in order to maximise interest and reduce exposure. Interest is added to the portfolio each month.

13 DEBTORS

	2024 £	2023 £
Gift Aid recoverable	4,970	7,486
Prepayments & accrued income	841,121	1,860,583
	846,091	1,868,069

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.

14 LIABILITIES

	2024 £	2023 £
Research grants not yet claimed	3,314,248	2,765,671
Accruals	27,784	38,790
Other creditors	75,126	122,107
Due within 12 months	3,417,158	2,926,568
Research grants due after 12 months	3,000,554	2,843,840
	6,417,712	5,770,408

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 funds represents money set aside by the Trustees for future research grants and for the campaign, launching a programme with the vision to radically advance the treatment and prevention of epilepsy.

	Designated Funds			
	Research Fund 2024 £	#Every1Ending Epilepsy 2024 £	General Fund 2024 £	Total Unrestricted Funds 2024 £
Balance as at 1 April 2023	2,213,953	280,218	900,000	3,394,171
Net incoming resources	166,322	(86,249)	704,028	784,101
Transfer between funds	704,028	-	(704,028)	-
Balance as at 31 March 2024	3,084,303	193,969	900,000	4,178,272

Unrestricted Funds 2023

	Designated Funds			
	Research Fund 2023 £	#Every1Ending Epilepsy 2023 £	General Fund 2023 £	Total Unrestricted Funds 2023 £
Balance as at 1 April 2022	1,388,488	350,000	900,000	2,638,488
Net incoming resources	-	-	755,683	755,683
Transfer between funds	825,465	(69,782)	(755,683)	-
Balance as at 31 March 2023	2,213,953	280,218	900,000	3,394,171

16 RESTRICTED FUNDS

	1 April 2023 £	Incoming Resources £	Resources Expended £	Transfers 2024 £	31 March 2024 £
Research grants	-	1,513,851	-	(1,513,851)	-
Priority Setting Partnership	-	20,000	(20,000)	-	-
Aisling Burnard Award	-	150	(302)	152	-
Shape Network	-	15,000	(20,092)	5,092	-
Celine Newman bursary	1,413	-	(3,360)	1,947	-
	73,242	1,549,001	(43,754)	(1,506,660)	-

The Institute supports a wide range of research, from experimental studies of epilepsy, including laboratory research of the cellular and molecular mechanisms of epilepsy, to novel diagnostics and treatments for the clinical management of people living with epilepsy.
Transfers represent expenditure incurred in a previous year from unrestricted funds, or small overspends against a restricted fund.
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.
The Aisling Burnard Award was a prize awarded by AMRC in honour of a past CEO.
The Priority Setting Partnership forms part of the major strategy for the Institute.

Restricted Funds 2023

	1 April 2022 £	Incoming Resources £	Resources Expended £	31 March 2023 £
Research grants	-	1,750,897	(1,750,897)	-
Shape Network	67,382	1,695	(69,077)	-
Celine Newman bursary	5,860	-	(4,447)	1,413
	73,242	1,752,592	(1,824,421)	1,413

17 ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total Funds 2024 £
Total assets	10,595,984	-	10,595,984
Current liabilities	(3,417,158)	-	(3,417,158)
Creditors falling due after more than 1 year	(3,000,554)	-	(3,000,554)
	4,178,272	-	4,178,272

Analysis of net assets between funds 2023

	Unrestricted Funds 2023 £	Restricted Funds 2023 £	Total Funds 2023 £
Total assets	9,164,579	1,413	9,165,992
Current liabilities	(2,926,568)	-	(2,926,568)
Creditors falling due after more than 1 year	(2,843,840)	-	(2,843,840)
	3,394,171	1,413	3,395,584

18 RELATED PARTY TRANSACTIONS

The field of epilepsy research is highly specialised and for the Epilepsy Research Institute UK to function effectively it is vital that leading practitioners 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 Institute UK, but they must declare any conflicts of interest concerning grant applications and are excluded from any discussion regarding the merits of such applications. In 2024, no new grants were awarded to Trustees as Lead Applicants. However, there were three new awards where Trustees were listed as a co-applicant or co-investigator. For these awards, no direct salary or salary contribution was paid for the Trustee's involvements. These included: Professor Matthew Walker – Co-applicant for the project 'Development of a breath test for the diagnosis of epilepsy and the prediction of seizures' Professor Anthony Marson – Co-investigator for the North West Doctoral Training Centre Professor Anthony Marson – Co-investigator for the project 'An international study to investigate and optimise the safety of discontinuing Valproate in young men and women with epilepsy' In the previous year, 2023, a co-funded award with Angelini Pharma of £200k was made to Professor Mark Richardson as lead applicant. The funding split was £170k from Angelini Pharma and £30k from Epilepsy Research Institute UK. There were no awards during that year where Trustees were co-applicants/ investigators. Additionally, The University of Liverpool were reimbursed for time for Professor Anthony Marson spent with the Institute in connection with his role as Institute Programme Director. In 2023-24, this was £32,795. In the previous year, 2022-23, this was £12,889.

19 LEASE COMITMENTS

A lease for office accommodation was taken out on 20 Sept 23 with the Royal College of Anaesthetists. The lease is for 3 years to 17 Sept 2026 and the following amounts are due:

April 24 - March 25	£60,123
April 25 - March 26	£60,123
April 26 - Sep 26	£27,749

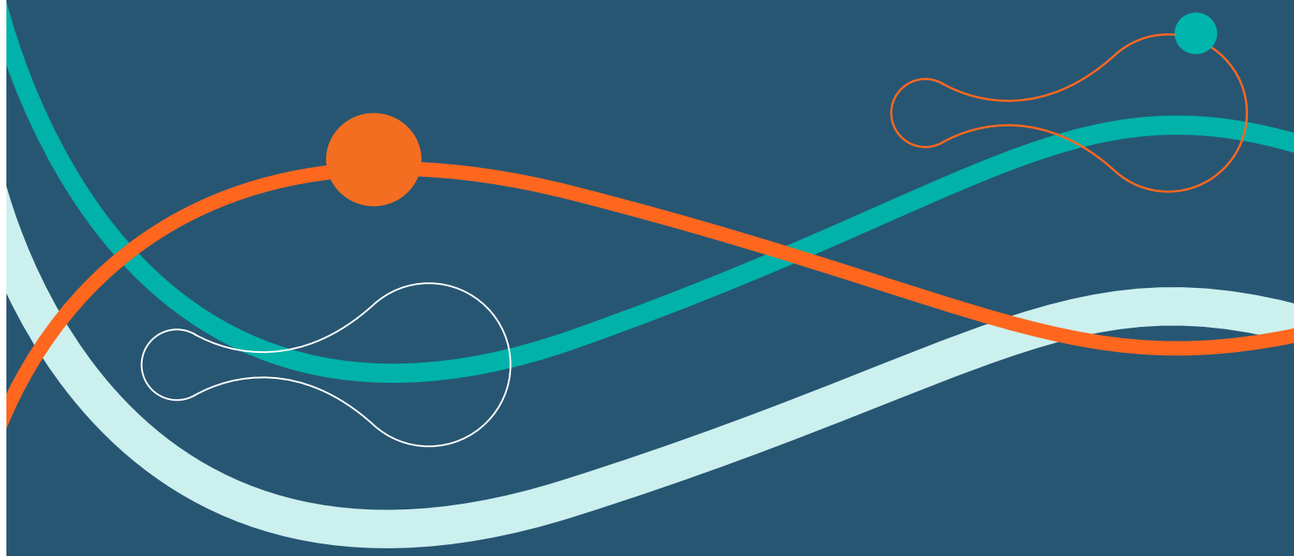
20 STATEMENT OF FINANCIAL ACTIVITY FOR THE YEAR ENDED 31 MARCH 2023 (PRIOR YEAR)

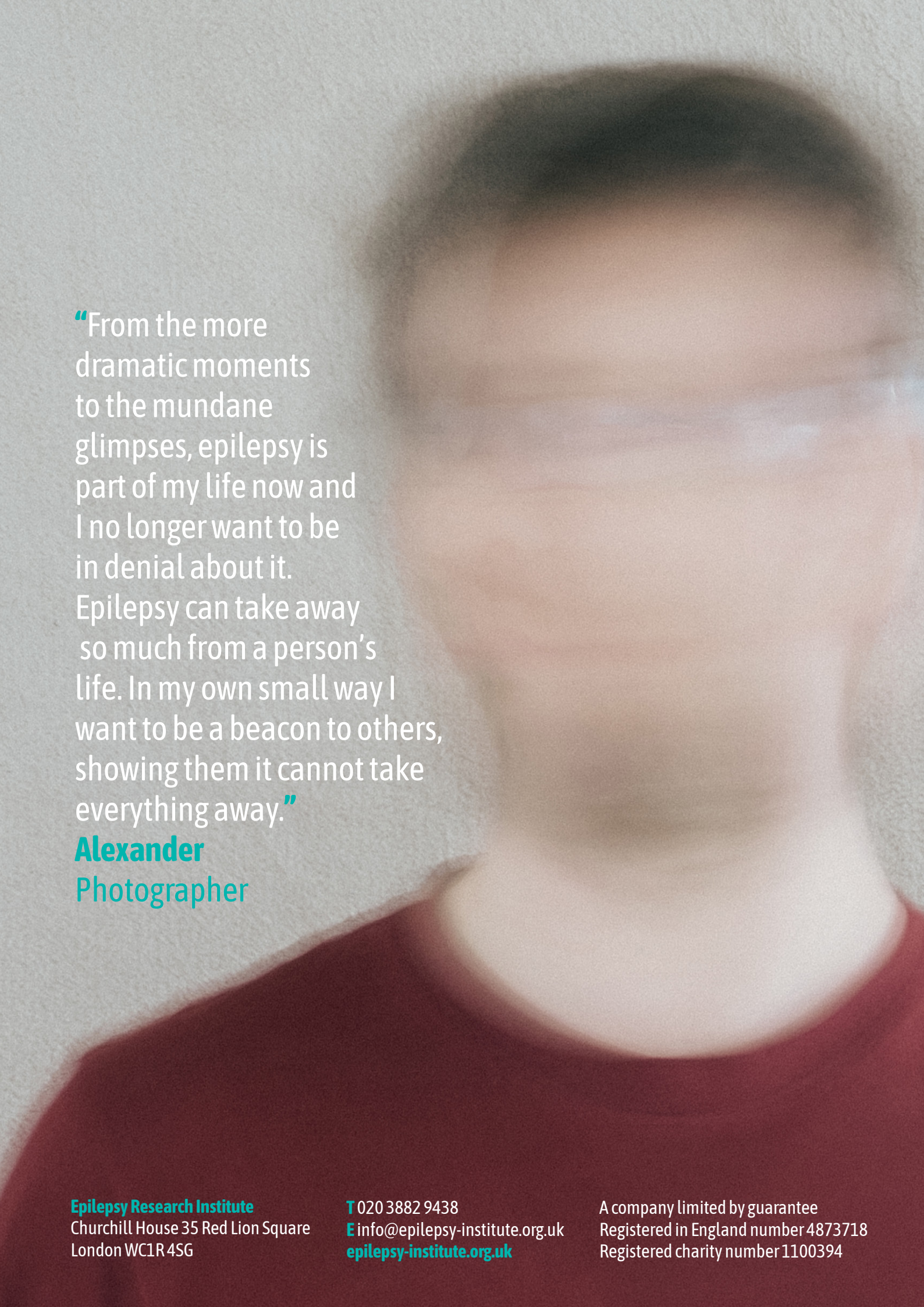
(Including the Income & Expenditure Account)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Income from:			
Donations and legacies	1,666,313	300,752	**1,967,065**
Grants	-	1,451,840	**1,451,840**
Other trading activities	18,193	-	**18,193**
Investments	168,272	-	**168,272**
Total Income	**1,852,778**	**1,752,592**	**3,605,370**
Expenditure on:			
Cost of raising funds			
Raising Funds	173,303	-	**173,303**
Charitable activities			
Research grants committed	1,705,986	-	**1,705,986**
Other research activities	705,613	73,524	**779,137**
Total charitable expenditure	2,411,599	73,524	**2,485,123**
Total expenditure	**2,584,902**	**73,524**	**2,658,426**
Net unrealised gains / (losses) on investments	(263,090)	-	**(263,090)**
Net income/(expenditure) for the year	(995,214)	1,679,068	**683,854**
Transfers between funds	1,750,897	(1,750,897)	-
Net movement in funds for the year	**755,683**	**(71,829)**	**683,854**
Reconciliation of funds:			
Total funds brought forward on 1 April	2,638,488	73,242	**2,711,730**
Total funds carried forward at 31 March	**3,394,171**	**1,413**	**3,395,584**

TOGETHER, WE WILL RADICALLY ADVANCE RESEARCH INTO EPILEPSY

For more information about our work, please visit our website: epilepsy-institute.org.uk/





“From the more dramatic moments to the mundane glimpses, epilepsy is part of my life now and I no longer want to be in denial about it. Epilepsy can take away so much from a person’s life. In my own small way I want to be a beacon to others, showing them it cannot take everything away.”

Alexander
Photographer

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Registered in England number 4873718
Registered charity number 1100394

EPILEPSY RESEARCH INSTITUTE UK

England & Wales - Charity number 1100394

Accounts

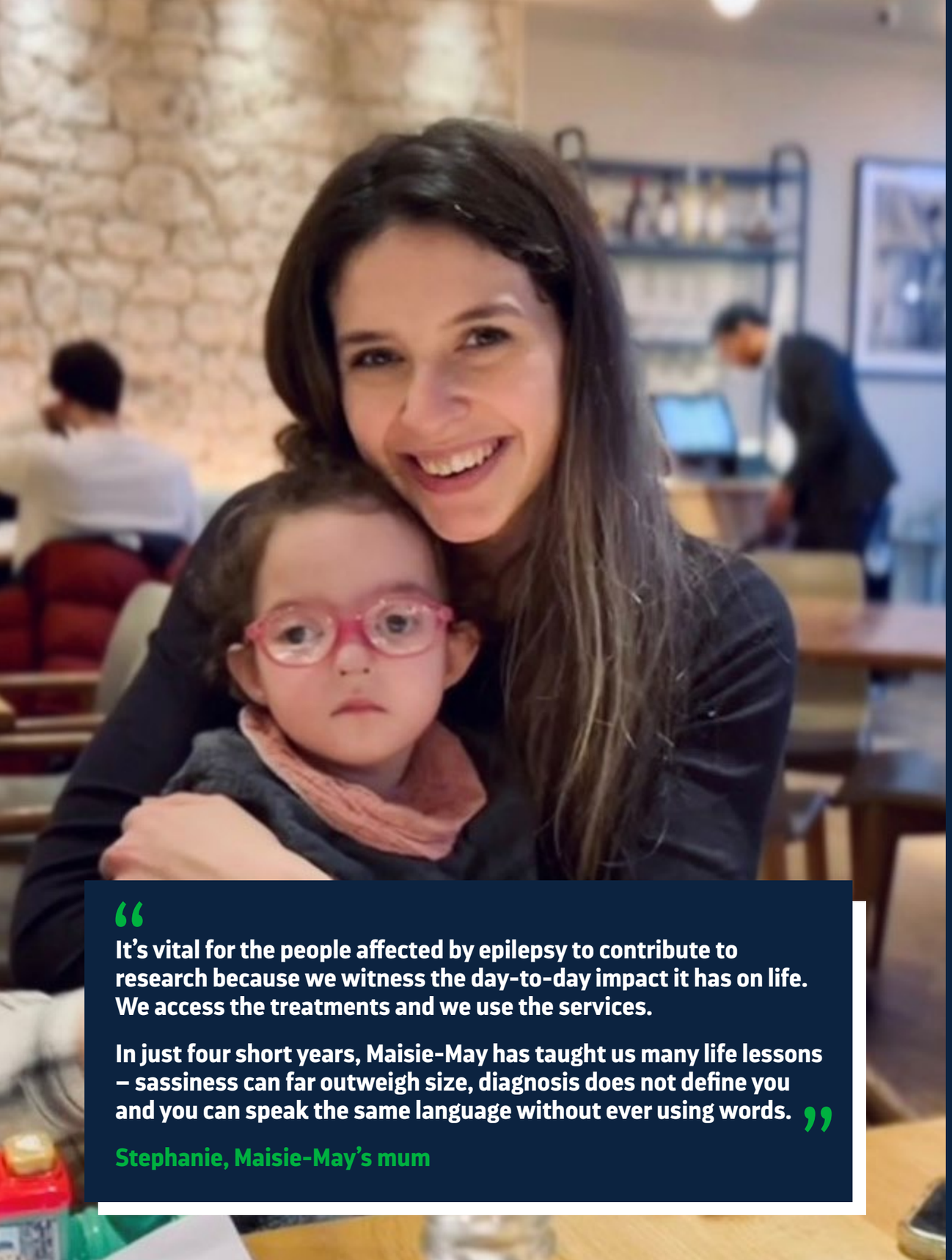
EPILEPSY RESEARCH UK

A LIFE FREE FROM EPILEPSY

Annual Review 2022/23



2023



“It’s vital for the people affected by epilepsy to contribute to research because we witness the day-to-day impact it has on life. We access the treatments and we use the services.

In just four short years, Maisie-May has taught us many life lessons – sassiness can far outweigh size, diagnosis does not define you and you can speak the same language without ever using words.”

Stephanie, Maisie-May’s mum

CONTENTS

Page 4 A message from our Chair & Chief Executive

Page 6 Our research in 2023

Page 12 Our journey to becoming the Epilepsy Research Institute

Page 18 Funding cutting edge research

Page 26 Building the epilepsy research system

Page 30 Influencing change

Page 36 The Institute

Page 40 Thank you

TRUSTEES’ REPORT AND FINANCIAL STATEMENTS

Page 2 Reference and administrative details

Page 3 Objectives and activities

Page 10 Independent auditor’s report

Page 14 Statement of financial activities

Page 15 Balance sheet

Page 16 Statement of cash flows

Page 17 Notes to the financial statements

A MESSAGE FROM OUR CHAIR & CHIEF EXECUTIVE



Professor Matthew Walker
Chair of Trustees



Maxine Smeaton
Chief Executive

We'd like to start our message with how we ended the year. This development is simply too big not to be the first thing we acknowledge when looking back over what we achieved in 2022/23. We began the year as Epilepsy Research UK, and we've ended it with the go-ahead from government to become the *Epilepsy Research Institute UK*. Research institutes have a reputation of advancing science, developing the research ecosystem and building the UK's capacity in many fields. Now, it's epilepsy's time.

This autumn we will become the **Epilepsy Research Institute UK**. While our vision of ***a life free from epilepsy*** remains the same, our remit is now bigger and includes building research capacity across the UK. Of course, much of our work in the last few years has been focused on capacity-building epilepsy research, and that's why this new development is a natural next step, as well as a pivotal moment in our 30 year history.

We know the devastation epilepsy causes people living with the condition and their loved ones. We share the frustrations of people affected by epilepsy, watching on as game-changing medical advances and breakthroughs happen in other conditions, while epilepsy research investment is hampered by a lack of funding and attention.

Historically, epilepsy has not been a 'political' condition. It hasn't commanded the attention other conditions have and its impact has not been widely recognised. The effects of this go far beyond the lab. This underfunding and lack of attention has impacted every single person living with the condition, from the treatment they receive to their quality of life. When we called out the chronic underfunding of epilepsy research investment in 2018, with the publication of the **#ALifeInterrupted** report, we also took a long, hard look at ourselves.

"We concluded there was more we could do for research into epilepsy than simply funding it."

While the investment we make in research and researchers has helped to develop life changing innovations for people with epilepsy, there's a limit to how much we can fund ourselves. And while progress has been made in the areas of drug development, genetics, gene therapy, surgical interventions and treatment trials, we are yet to find the underlying causes of epilepsy for the 65% of people for whom there is currently no known cause.

We know that research cannot flourish without the right level of investment and the right infrastructure. In 2019, we published our **Going Further** strategy for 2020-25, which focused on capacity building programmes that aimed to develop an ecosystem for epilepsy research to flourish.

Now, in year three of our Going Further strategy, we're at a pivotal moment. By becoming the Epilepsy Research Institute, we will become a central hub for research into epilepsy and, crucially, we will be able to drive strategic investment through the work of our national research collaborative, #Every1EndingEpilepsy.

As the Institute, we will promote collaboration between those working in research in universities, in the NHS, in industry and with funders and our epilepsy and associated condition charities. We will ensure people affected by epilepsy can get involved in all aspects of research. We will drive increased strategic investment. Ultimately, we will radically advance innovations for the 630,000 people living with epilepsy in the UK.

The Institute will also play a key role in bringing the research communities and charities together under a shared vision and mission. We would like to thank our Founding Partners for their support – Young Epilepsy, Epilepsy Action, Epilepsy Scotland and the International League Against Epilepsy (British Branch).

We know collaboration is the key to accelerating progress. It is thanks to the efforts of the epilepsy community, our charity partners, healthcare professionals, researchers and, of course, all those personally affected by the condition, that we have been able to reach this pivotal moment. We would also like to thank our supporters. It's thanks to them that we are in such a strong position, both financially and organisationally, to create a brighter future for everyone affected by epilepsy.

"The Institute will be a seismic shift in the landscape. Epilepsy research is no longer a scientific backwater."

It's on the global stage and on the political agenda. There is a real sense of hope and anticipation that science will finally deliver for people living with epilepsy.

As this report shows, we are tackling epilepsy on many fronts. We will continue to be relentless in our pursuit to radically advance research into epilepsy and end the devastation caused by epilepsy.

Professor Matthew Walker
Chair of Trustees

Maxine Smeaton
Chief Executive

OUR RESEARCH IN 2023

Thanks to the generosity of our supporters, we invested £1.7 million of research funding as part of our 2023 annual grant awards – our largest single research investment to date. The research projects we funded include a broad range of science from basic, clinical and data research, which will drive innovations in the diagnosis, treatment and prevention of epilepsy.

RESEARCH GRANTS IN 2023

EMERGING LEADER FELLOWSHIP AWARDS

TITLE	AMOUNT	LEAD APPLICANT	INSTITUTION
Targeting seizures and cognitive comorbidities with gene therapy	£246,016	Dr Amy Richardson	UCL Queen Square Institute of Neurology
New target discovery for Tuberous Sclerosis treatment	£249,939	Dr Amanda Almacellas Barbanoj	UCL Queen Square Institute of Neurology
New therapies against epilepsy combining sleep and cellular stress genes	£245,963	Dr José Prius Mengual	University of Oxford

ENDEAVOUR PROJECT GRANTS

TITLE	AMOUNT	LEAD APPLICANT	INSTITUTION
Adapting and evaluating a problem-solving intervention for children aged 9-12 years with epilepsy	£155,584	Prof Anna Adlam	University of Exeter
Can metabolism of lysine be targeted to treat epilepsy in tuberous sclerosis complex (TSC)?	£174,495	Dr Felix Chan	Aston University
Do babies with genetic epilepsy have more excitable neurons?	£163,444	Dr Amy McTague	UCL Great Ormond Street Institute of Child Health
How safe are anti-seizure medicines used in pregnancy?	£173,842	Dr Anita McGrogan	University of Bath

EXPLORE PILOT STUDIES

TITLE	AMOUNT	LEAD APPLICANT	INSTITUTION
Investigating anti-seizure medications and breastfeeding using the UK and Ireland Epilepsy and Pregnancy Register	£29,969	Dr John Craig	Belfast Health & Social Care Trust
How can the new generation of MEG machines help patients awaiting epilepsy surgery?	£29,583	Dr Caroline Witton	Aston University
Identification of brain cell mutations in focal epilepsy	£29,988	Prof Maria Thom	UCL Queen Square Institute of Neurology

INNOVATIONS IN HEALTHCARE RESEARCH AWARDS

TITLE	AMOUNT	LEAD APPLICANT	INSTITUTION
Using Natural Language AI to identify predictors of refractory epilepsy in NHS Electronic Health Records	£199,595	Prof Mark Richardson	King's College London
Using large-scale data and artificial intelligence for refractory epilepsy research	£50,000	Dr Owen Pickrell	Swansea University

FUNDING RESEARCH ACROSS THE UK

This year's funded research will take place in universities and hospitals throughout the UK, including the University of Oxford, University College London (UCL), University of Exeter, Aston University, University of Bath, Swansea University and Belfast Health & Social Care Trust.



The researchers discussed their ground-breaking new projects in a series of short films. If you'd like to learn more about each project, they're well worth watching.



VIEWPOINT

“Funding research of the highest scientific quality and rigour”



Professor Mike Cousin Chairs the Scientific Advisory Committee (SAC). The SAC assesses the research funding applications we receive and here, Professor Cousin provides an overview of the projects funded in our 2023 Research Awards.

Since becoming Chair of the Scientific Advisory Committee in 2020, I’ve witnessed a huge increase in research funding made by Epilepsy Research UK, thanks to the incredible generosity of our supporters. We endeavour to ensure that every penny supporters raise is targeted to research that’s of the highest scientific quality and rigour. Importantly, this support is also enabling the charity to sculpt the future research landscape by generating additional capacity in epilepsy research.

This is being done at the very early career stage, using Epilepsy Research UK Doctoral Training Centres to attract the brightest minds to our field, but also in cultivating leaders of the future, via the Emerging Leader Fellowships. In addition to this, we support the very best science in the form of both Endeavour Project Grants and Explore Pilot Studies.

“The projects Epilepsy Research UK funded in 2023 feature a combination of basic, clinical and data science, and all of which relates to the UK Epilepsy Top Ten Research Priorities.”

We awarded three Emerging Leader Fellowship Awards to bridge the gap between fundamental and translational epilepsy research. These three researchers are at the forefront of research into new epilepsy therapies, and we are excited by them and their research programmes.

We also awarded four Endeavour Project Grants, which address both basic epilepsy mechanism and research that may change clinical practice. ‘Big data’ is a rapidly developing research area and we have awarded two Innovations in Healthcare Awards, to unlock the potential of big data, including using artificial intelligence, for people living with epilepsy. Finally, to test and develop exciting new ideas, we awarded three Explore Pilot Studies.

Making these awards is the culmination of nine months of effort by our fantastic SAC: a collection of expert scientists and clinicians, who all offer their services to Epilepsy Research UK voluntarily. The SAC integrate their own expertise with independent external peer reviewers, as well as feedback from the Epilepsy Research UK Shape Network through Application Clinics.

It’s been a privilege to Chair the SAC over the past three years and see the potential impact of the projects we fund on the lives of people affected by epilepsy. Research into basic mechanisms, clinical outcomes and the translation of new therapies is all being accelerated by our fantastic supporters, and it’s a humbling experience to assist in the small way that we do.

2023 RESEARCH AWARDS IN NUMBERS

£1.7m

IN THIS YEAR’S RESEARCH AWARDS - OUR HIGHEST SINGLE RESEARCH INVESTMENT

12

NEW STUDIES

50

RESEARCHERS AND COLLABORATORS

12

INSTITUTIONS ACROSS THE UK

AND INTERNATIONAL COLLABORATIONS IN IRELAND, NORWAY AND THE US

CURRENTLY FUNDING OVER 80 PROJECTS IN TOTAL

OUR JOURNEY TO BECOMING THE EPILEPSY RESEARCH INSTITUTE

As we transition to become the Epilepsy Research Institute, we are taking a look back at our journey over the last five years.

EPILEPSY RESEARCH UK: THE STORY SO FAR...

When Epilepsy Research UK was formed in 2008, our mission was clear – to drive forward research into epilepsy. Over the last 15 years, we have steadily grown our income, our research investment and our influence.

We're now in a position to award £1.7 million a year in fellowships, PhD studentships and research grants, building the capacity of epilepsy research centres throughout the UK. We currently fund over 80 projects, including clinical research, to advance the medical care and management of people living with epilepsy, and lab-based scientific research, investigating the causes and methods for improving the diagnosis, treatment and prevention of epilepsy.

Since we began, our ambition to end epilepsy has never faltered. But, and it's a big but – ambition is not enough. While the research we fund has led to clinical innovations and sparked further investment, progress for epilepsy has lagged behind other conditions.

As you know, epilepsy research has been chronically underfunded. This has greatly hampered progress and is the reason why today, much like back in 2008, hundreds of thousands of people are still living with the threat of uncontrolled seizures and why in the UK alone, three people still lose their lives to epilepsy every day.

DRIVING STRATEGIC CHANGE

In 2020, we called out the stark inequalities in neurological research funding when we published our **#ALifeInterrupted – Shaping the Future of Research into Epilepsy** report. Alongside this, we launched a campaign to raise awareness of the chronic underfunding of epilepsy research.

But calling it out wasn't enough. To shift the dial in our favour, we needed to channel our ambition to end epilepsy into some big ideas. Our campaign called on people affected by epilepsy to join our newly established **Shape Network**. This network has since become the UK's largest epilepsy patient and public involvement and engagement (PPIE) group. Over 350 research-interested people affected by epilepsy are now actively involved in our research assessment work and partnering on research programmes.

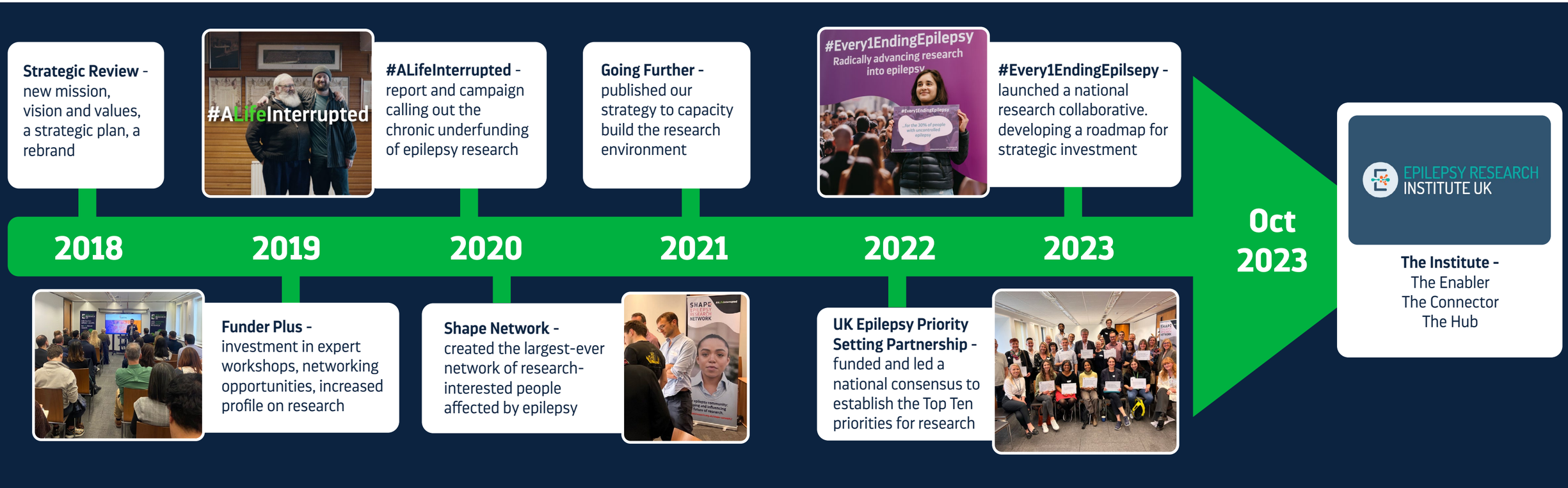
The following year we published our **Going Further** strategy, which detailed our plans to enhance epilepsy research on multiple fronts, including a greater focus on capacity-building the research environment. This programme formed the building blocks of this moment – a shift change we believe could deliver our vision of a life free from epilepsy.

One of these building blocks was focusing the research community on what matters most for people with epilepsy. Last year we partnered with the James Lind Alliance (JLA) and National Institute for Health Care Research (NIHR) to identify the **Top Ten research priorities** for the epilepsy community. This is now providing researchers with the evidence that their research is a priority for people affected by epilepsy and will lead to increased investment.

To help drive large-scale investment, we have funded and led a national epilepsy research collaborative, **#Every1EndingEpilepsy.** This research strategy committee is working to design and deliver an epilepsy research roadmap to radically advance research into epilepsy.

OUR PIVOTAL MOMENT IS NOW

Our work over the last four years has led us to a big moment in our history. In March 2023, we received permission from the government to become the Epilepsy Research Institute UK. The term 'Institute' is controlled by the government, and only available to those with a track record of success in their field and who operate nationally at the highest levels. Becoming the Epilepsy Research Institute UK will provide us with the unique capability to convene and coordinate the research community. The Institute will unite everyone in a common purpose to radically advance epilepsy research. If you'd like to read more about this exciting development, go to **page 36**.





Click here to read the Going Further strategy on our website

GOING FURTHER

With the publication of our five-year Going Further strategy in 2020, we set out our plans to strengthen the epilepsy research ecosystem through capacity building programmes to support greater investment in research.

Our three strategic priorities detailed how we planned to invest in research and researchers, alongside how we aimed to capacity build the research environment to accelerate progress. Our strategy laid out the path to achieving our ultimate goal, ***a life free of epilepsy***.

THREE STRATEGIC PRIORITIES - OUR TARGETED APPROACH

PRIORITY 1

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

PRIORITY 2

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

PRIORITY 3

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

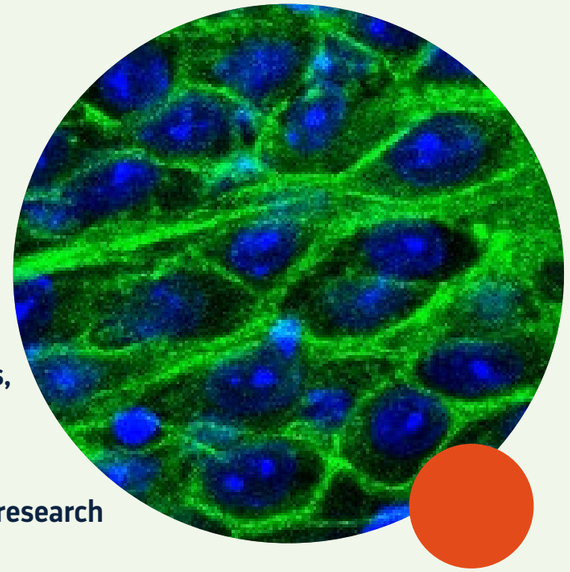
By the end of this strategy period in 2025, our goal was to have made a significant contribution to levelling up epilepsy research, to inspire young researchers to devote their careers to the field and to see greater collaboration and knowledge sharing across the epilepsy community.

Over the next few pages, you will see the progress we have made on our strategy, and therefore, the progress we have made in driving this change.

FUNDING CUTTING EDGE RESEARCH

Our annual research awards support only the best research investigating the causes, diagnosis and treatment of epilepsy. Since 2019, Epilepsy Research UK has also been working to build the capacity of the epilepsy research community, through projects such as Doctoral Training Centres and forging partnerships and collaborations with industry and fellow charities.

SUPPORTING RESEARCH AT ALL STAGES



Our annual research awards support projects spanning basic, clinical and data science research to drive innovations in the treatment and prevention of epilepsy. The awards are selected by our Scientific Advisory Committee (SAC) – a panel of the UK's leading neurologists, neuroscientists and epilepsy researchers. In a nine-month process applications are tested, probed and interrogated. The SAC then recommends the most promising high-quality research to our Board of Trustees.

The potential of this year's and all previous years' research awards is huge. From targeting seizures with gene therapy to identifying brain cell mutations, our research is tackling epilepsy and its devastating impact on many fronts. Alongside funding cutting-edge projects, we are also creating leaders in the field through our Fellowship Awards.

EMERGING LEADER FELLOWSHIP AWARDS

Our Fellowship Awards provide funding for scientists planning to develop a track record in epilepsy research and transition into a leadership role. The fellow must not only be an excellent candidate, but also submit an exceptional proposal with great potential outcomes for people affected by epilepsy. The fellowships place these ambitious and talented researchers at the heart of epilepsy research, where they can further develop their scientific expertise.

ENDEAVOUR PROJECT GRANTS

Endeavour Project Grants support fundamental science and clinical research investigating the causes, diagnosis or treatment of epilepsy and associated conditions. These grants help to unlock the promise and potential of early hypotheses, that are based on pilot data by further investigation, with the aim of substantially contributing to furthering knowledge of epilepsy.

EXPLORE PILOT STUDIES

Science has to start somewhere. Every breakthrough started with an idea that had to be tested and further developed. Our Explore Pilot Studies provide an opportunity to testbed new ideas and explore novel areas of research. Information gathered from pilot studies enables researchers to obtain larger funding to progress their cutting-edge research.

DOCTORAL TRAINING CENTRE PARTNERSHIPS TO SECURE THE FUTURE OF RESEARCH

We are ensuring we are securing the future of epilepsy research by providing opportunities for the best and brightest young minds to develop into tomorrow's future clinical and research leaders. In 2022, we set up two Doctoral Training Centres (DTC) at the University of Edinburgh and Newcastle University.

"Doing a PhD can be quite an isolated experience, but through the DTCs we will build cohorts with shared training that spans the whole field of epilepsy research. This will also allow students to place their own research in the wider context of everything, from genetic diagnosis to predicting how seizures develop, from technology to drug development. The Edinburgh and Newcastle DTCs are going to work together to share training, building an even bigger and better cohort effect. Crucially, the experience of people with epilepsy will be embedded throughout this training – their input is vital to ensuring that research is appropriately focused, and who better to inspire the next generation of researchers?"
Professor Cathy Abbot, University of Edinburgh



INVOLVING PEOPLE AFFECTED BY EPILEPSY

Importantly, all research funded through our grant round now involves people living with or affected by epilepsy. Through our Shape Network Application Clinics, researchers and people affected by epilepsy can discuss and debate research grant proposals.

Our Shape Network is now the largest Patient and Public Involvement and Engagement (PPIE) group focused on epilepsy, with over 350 members. For researchers, our network enables studies to be more effective, relevant and cost effective. It also means we can ensure the research we fund is focused on the most important outcomes for people living with epilepsy.

"As a Shape Network member I have been involved with the Application Clinics, through which I, along with other Shape Network members, met with shortlisted grant applicants to discuss their applications, including how best to involve people affected by epilepsy in the research, and how best to communicate this research to a non-scientific audience. It was a fascinating experience and it has been brilliant to see that some of these applications have been awarded funding and I am so excited to hear about their progress in the coming months and years."
Rebecca, Shape Network member



IMPROVING TREATMENT AND CARE

Epilepsy is a complex condition - not just to manage, but also to research. To push forward the care people living with the condition can access today, we fund healthcare research to build clinical knowledge and influence clinical practice.

The Covid-19 pandemic saw a rapid acceleration in new technologies and remote consultations for routine and emergency care. That's why in 2020, following an urgent appeal for proposals, we funded urgent 'Innovations in Healthcare' grants to drive the development of new innovations that work for people with epilepsy. We have boosted our portfolio of Innovations in Healthcare grants, with further awards made in 2022.

EPILEPSY RESEARCH UK & ANGELINI PHARMA INNOVATIONS IN HEALTHCARE PROJECT

Through our strategic alliance with Angelini Pharma, we awarded Professor Mark Richardson at King's College London funding for a data-driven research collaboration using artificial intelligence and large-scale NHS clinical data records. In collaboration with Health Data Research UK, the project will seek to understand and predict important clinical outcomes in refractory epilepsy. By identifying new information about the risk factors for developing refractory epilepsy, it will ultimately enable researchers to develop new strategies to prevent it.



"Over the last decade, NHS hospitals have started to adopt electronic systems for collecting medical records. As a result, there is detailed information about health status related to tens of thousands of people with epilepsy. We have developed systems to extract highly detailed information from electronic health records, maintaining confidentiality and privacy of the information. We can analyse this information using artificial intelligence to track the course of epilepsy in thousands of people and make a much better attempt to identify the factors that predict refractory epilepsy."
Professor Mark Richardson

EPILEPSY RESEARCH UK INNOVATIONS IN HEALTHCARE PROJECT

Dr Owen Pickrell and his colleagues at Swansea University will use artificial intelligence and machine learning algorithms to extract key information from electronic health records to identify risk factors for refractory epilepsy. This is a rapidly developing research area and a valuable investment in this ground-breaking work.

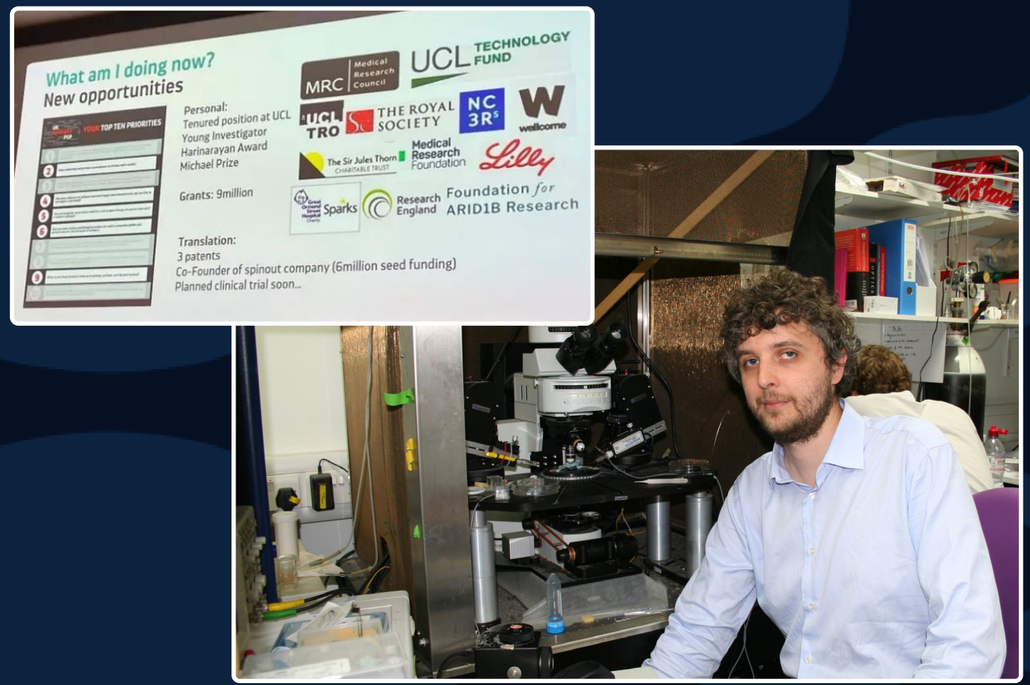


LEVERAGING RESEARCH FUNDING

Over the last five years, our investment in research has leveraged an additional £31.4million in follow-on funding from other institutional funders – a ratio of £5.94 leveraged funding for every £1 invested by Epilepsy Research UK.

£1 £5.94

Former Emerging Leader Fellow, Professor Gabriele Lignani, is one of the many ERUK-funded researchers who has secured further funding after receiving an ERUK grant. Gabriele has obtained £9 million in follow-on funding and has so far translated his gene therapy in three patients. Gabriele exemplifies the importance of our Emerging Leader Fellowship Award and how it enables researchers to become leaders working on ground-breaking research. It also showcases how our initial investment has leveraged millions in follow-on funding.



FUNDING COLLABORATIONS AND PARTNERSHIPS

Epilepsy is too big for one charity, for one organisation and for one laboratory. By collaborating with other organisations, we strengthen our fight against the condition. Together we are stronger and only by working together will we stand the best chance of driving forward major innovations.

Epilepsy is not just one condition, it's an umbrella term for over 40 different conditions and syndromes. It also often co-occurs with other conditions, so by partnering with disease-specific charities, we can help to reveal new insights by sharing our collective expertise. This also avoids duplicating efforts and maximises our research funding and impact.

Over the last three years, we have establish co-funded research fellowship awards with Autistica, Young Epilepsy, Stroke Association and the Association of British Neurologists. In 2022/23, we added to our growing portfolio of co-funded research fellowships with a funding collaboration with the Tuberous Sclerosis Association (TSA) .

The Epilepsy Research UK Tuberous Sclerosis Association Fellowship Award will support and develop a future leader investigating tuberous sclerosis complex (TSC)-associated epilepsy. This research will improve our understanding of the relationship between TS and epilepsy, offering new targets for the drug and gene therapies so urgently needed for those living with TSC-associated epilepsy.



Dr Amanda Almacellas Barbanoj £249,938 over 30 months awarded in 2023

COLLABORATING FOR CARE

Our collaborations are not just focused on research. Since the publication of our Going Further strategy, we have co-funded healthcare grants with SUDEP Action, Epilepsy Society and Epilepsy Action. These grants enable us to ensure any new development in epilepsy care, particularly those that were brought in during the pandemic, are both effective and designed for people with epilepsy. The study results will be widely shared with both our supporters and the wider epilepsy community.

Further to research and healthcare focused collaborations, we also join forces with other organisations to gather evidence to help inform future research and shine a light on underserviced areas. We worked with Autistica and Young Epilepsy to better understand the prevalence and incidence of epilepsy in autism. The result, an Autism and Epilepsy dossier, highlighted areas where research is needed and where it will make most difference to people who are autistic and have epilepsy.

COLLABORATING WITH CORPORATES AND COUNCILS

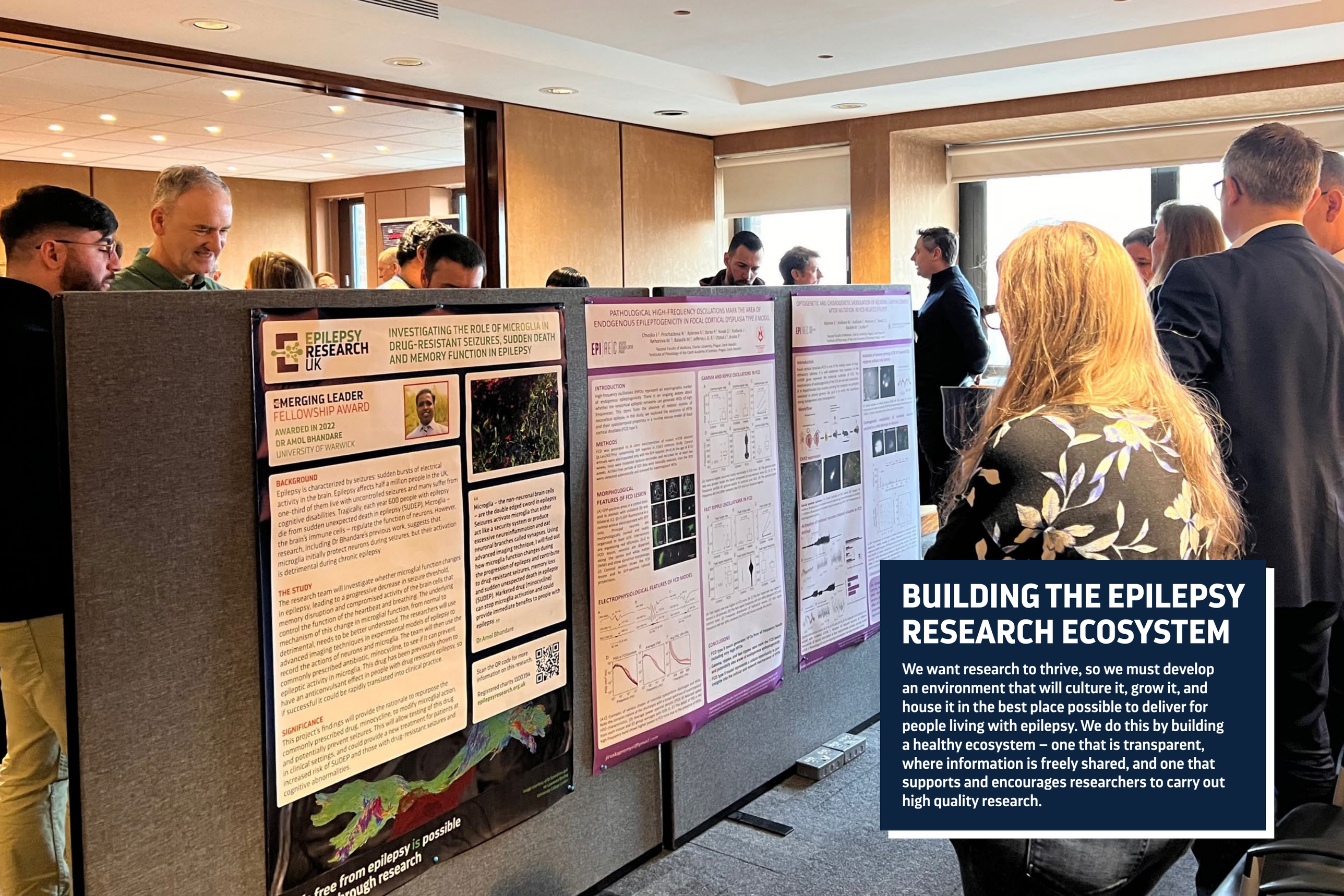
Last year, we entered into a new strategic alliance with Italian-based pharmaceutical company Angelini Pharma to support data-driven research into epilepsy. Together, we have commissioned a study that will use large-scale NHS clinical data records to understand and predict important clinical outcomes in refractory epilepsy. We made the first award of this partnership to Professor Mark Richardson at King's College London in September **(see page 22).**

In August 2022, we announced a partnership with the Medical Research Council (MRC) Nucleic Acid Therapy Accelerator (NATA), to co-fund a fellowship investigating pioneering, long-term treatments for epilepsy. NATA was founded by the MRC to accelerate the development of these promising new treatments and advance the technology used to manufacture and administer them.

This fellowship award of £250,000 will fund an early-career researcher for two years to investigate the role of nucleic acids in treating epilepsy and become a future leader in this field. During National Epilepsy Week, we announced that Dr José Prius Mengual from the University of Oxford has been awarded funding for this innovative project.

"During my previous MRC early career position, I collaborated in investigating the molecular and electrical signatures of epilepsy in the brain. This experience has made me acutely aware of the pressing need for novel approaches in treatments against epilepsy. Innate curiosity and a drive to improve things have motivated me to develop a project focused on genetic therapies, that will ultimately result in better clinical interventions and aim to significantly improve the lives of people affected by epilepsy. I am eagerly looking forward to seeing the positive impact my efforts will have on people's lives."
Dr José Prius Mengual





BUILDING THE EPILEPSY RESEARCH ECOSYSTEM

We want research to thrive, so we must develop an environment that will culture it, grow it, and house it in the best place possible to deliver for people living with epilepsy. We do this by building a healthy ecosystem – one that is transparent, where information is freely shared, and one that supports and encourages researchers to carry out high quality research.

DISSEMINATING KNOWLEGDE

We know information sharing encourages connections and collaborations between researchers. It allows researchers to build on the work of others and informs their future research. This year, we continued to grow our dissemination activities.

EPILEPSY RESEARCH UK AT THE ILAE 2022 ANNUAL SCIENTIFIC MEETING

World-leading clinicians and researchers gathered for the International League Against Epilepsy (ILAE) Annual Scientific Meeting in October 2022, to hear the latest developments in areas including novel treatments, artificial intelligence and neurosurgery. The work of Epilepsy Research UK featured heavily throughout the conference, including the unveiling of the Top Ten research priorities of the UK Epilepsy Priority Setting Partnership (PSP) and the #Every1EndingEpilepsy programme.







There were 15 Epilepsy Research UK-funded researchers, trustees and SAC members chairing sessions and discussing findings from their pioneering projects, and for the first time, PhD students from our two Doctoral Training Centres also attended. Once again, we ran the Neurobiology of Epilepsy session, where we heard from shortlisted early career researchers competing for the Céline Newman Neurobiology of Epilepsy Prize. This year's award went to PhD student Kate Hills from the University of Manchester, for her presentation on 'Mapping epileptiform activity using graphene-based thin film devices in a model of glioblastoma-associated epilepsy.'

FIRST NAVIGATOR SERIES SYMPOSIUM ON GENETIC THERAPIES

For over a decade, our International Expert Workshops acted as a catalyst for collaborative research activity, bringing together hundreds of researchers from around the world. The COVID-19 pandemic temporarily halted our workshop programme, but we continued to promote the sharing of ideas and collaboration through the launch of the Navigator Series. In February 2023, leaders in genetic therapies for epilepsy from across the UK and Europe came together for the inaugural Navigator Series symposium. The one-day conference focused on genetic therapies for epilepsy and was chaired by Emerging Leader Fellow Dr Gareth Morris and our Scientific Advisory Committee Chair, Professor Michael Cousin.





COMMUNICATING RESEARCH

We are determined to ensure people affected by epilepsy and our supporters are able to stay up-to-date and informed about the research we fund. This year we continued to use our website as a hub for all the latest information and news on epilepsy research, through blogs and webinars.

Our Research Blogs provide an opportunity for clinicians, researchers and people affected by epilepsy to discuss research and epilepsy, with features on epilepsy and pregnancy, SUDEP, research participation and our Innovations in Healthcare Awards.







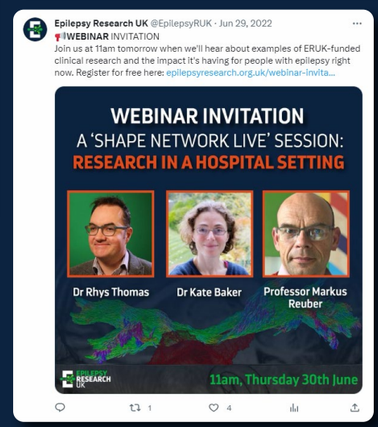
















INFLUENCING CHANGE

For a condition affecting so many, epilepsy has historically received so little. So little funding, so little attention, so little investment. Epilepsy Research UK is at the heart of rallying and building a community of those affected by epilepsy, researchers charities and other organisations to focus on epilepsy research and share a united voice calling for change.

FINDING OUR VOICE

In 2018, we found and raised our voice. We called out the glaring inequities in epilepsy research funding compared to other, less-prevalent conditions with the publication of our report, #ALifeInterrupted. The subsequent award-winning campaign featuring Doug and Ava, who are both living with epilepsy, shone a light on the human cost of the chronic underinvestment in epilepsy research.





Despite epilepsy being one of the most common, serious neurological conditions, just 0.3% of the £4.8 billion spent on health-related research is invested in epilepsy research.



This report was a significant chapter for Epilepsy Research UK, in that it led to the formation of our Shape Network patient and public involvement and engagement (PPIE) group. The network has since grown to be the UK's biggest communities of research-interested people living with epilepsy.

These two significant developments firmly put Epilepsy Research UK at the heart of rallying and building a community of people affected by epilepsy, researchers, charities and other organisations to focus on epilepsy research and share a united voice calling for change.

Our voice has since gotten stronger, enabling us to directly influence the landscape of epilepsy research. We have pushed for (and delivered) solid evidence to inform future research and healthcare innovations. We have rallied the community. And we will influence government and other funders to invest more into research. These next few pages will tell you how.

IDENTIFYING RESEARCH PRIORITIES

In 2022/23, we funded and led the UK Epilepsy Priority Setting Partnership (PSP). This landmark engagement programme was a once-in-a-generation, national consensus that collated and ranked the research priorities of the UK's epilepsy community to identify the Top Ten. By delivering the PSP Top Ten, we are influencing the direction of epilepsy research and ensuring we are focussed on the areas that matter most to the those affected.





This past year, we have continued to develop our plans for how we can best support research that answers the questions raised in the PSP. The research priorities also now form part of our SAC funding assessment process, and all the projects we fund must be related to the Top Ten unanswered research questions.

On the next page, you will read about the #Every1EndingEpilepsy national collaborative and how the PSP priorities have been integrated into the planning and shaping of a research roadmap and strategy. Read more about the process on **page 34**.

RADICALLY ADVANCING RESEARCH INTO EPILEPSY

#Every1EndingEpilepsy is our programme to radically advance research into epilepsy through investment, collaboration and action. In May 2022, we presented the programme at a research reception held at the Francis Crick Institute.

The event showcased #Every1EndingEpilepsy, featuring inspirational contributions from people affected by epilepsy and examples of the 'PSP in Action' presented by Dr Tim Tierney, Dr Zelekha Seedat and Professor Gabriele Lignani.

We are working to deliver a research framework and campaign to drive strategic investment, seeking a one-off multi-million-pound accelerator investment from institutional funders, and a commitment to long-term, sustainable funding for epilepsy research. Since the programme launched in 2022, we have brought together epilepsy research experts from across the country, building on their existing strengths, knowledge and experience to identify the challenges and gaps that must be urgently addressed to increase the capacity and capability required to fast-track research into epilepsy.



WORK IN 2023/24

We are now developing a roadmap using the four themes from the PSP. We will be calling on the epilepsy community to help us publicise the road map and encourage institutional funders to invest in the future of epilepsy research.

In 2024 we will launch a strategic communications campaign led by people affected by epilepsy, which will call on institutional funders to commit to a research investment of £100 for everyone living with epilepsy in the UK – that's £100 for every 1 in 100 – a £60 million total accelerator fund. We have seen this approach work in other disease areas. The time is now to level-up funding for epilepsy research.









THE INSTITUTE

At our research reception in May, George Freeman MP, Minister of State for Science, Research & Innovation, unveiled our plan to establish a national research institute. The Institute will drive strategic investment and capacity build the research ecosystem to radically advance the treatment and prevention of epilepsy.

> “I fully support the formation of the Epilepsy Research Institute UK. It is clear that progress will not be achieved by some extraordinary discovery one afternoon in a laboratory, but by incremental aggregation of different disciplines, multidisciplinary working partnerships and a combination of deep biological science, neural pathway mapping, AI and technologies that require our top laboratories, and research institutes around the world to work together.”

George Freeman MP
Minister of State for Science, Research and Innovation

WHAT THE INSTITUTE WILL DO

In October 2023, Epilepsy Research UK will become the Epilepsy Research Institute UK. Our vision of *a life free from epilepsy* remains unchanged. But our mission and purpose has now broadened. As the Institute, our mission is to radically advance research into the causes, prevention and treatment of epilepsy.

EPILEPSY RESEARCH INSTITUTE UK

OUR PURPOSE:

1. Convene, connect and capacity build the epilepsy research ecosystem
2. Drive strategic investment in epilepsy research
3. Fund research into epilepsy and associated conditions
4. Develop research partnerships and collaborations
5. Advocate and action the research priorities of people affected by epilepsy

The Institute will serve as a central hub for the epilepsy research ecosystem, developing partnerships and collaborations between academia, the NHS, industry, funders and patient organisations. Our ambition is to accelerate innovations for the 1 in 100 people living with epilepsy in the UK through increased strategic research investment, capacity building and research translation.

The Institute will embed the research programmes developed by the #Every1EndingEpilepsy steering group and use our influence to drive strategic investment into epilepsy research, creating a strong, vibrant and well-funded epilepsy research ecosystem.

OUR FOUNDING PARTNERS

We are proud to be joined by Young Epilepsy, Epilepsy Action, Epilepsy Scotland and the International League Against Epilepsy British Branch as the Founding Partners of the Epilepsy Research Institute UK. Our alliance and commitment to this mission aims to set the tone for a multidisciplinary culture of collaboration. We would like to thank the four Founding Partners for their unwavering leadership and support in developing an institute that will belong to everyone.



"Living a life free from epilepsy can only be achieved through research. The Epilepsy Research Institute UK will unite the epilepsy community in our collective ambition to stop epilepsy interrupting lives." Epilepsy Research UK Chair, Professor Matthew Walker

"The Institute will be pivotal in helping us to develop our UK capacity which ultimately will have an impact worldwide." Epilepsy Research UK President and International League Against Epilepsy (ILAE) Global President, Professor Helen Cross OBE





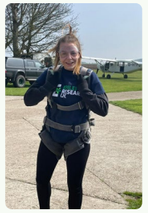
"We're delighted to be involved in the Epilepsy Research Institute UK as a Founding Partner. The Institute will drive much-needed investment into epilepsy research, putting the voices of people with the condition right at the heart of that work." Epilepsy Action Chief Executive, Philip Lee

"Working together as a Founding Partner of the national Epilepsy Research Institute UK will unlock the collaborative power of a strong multi-organisational research ecosystem driving vital research forward in a bid to accelerate innovations." Young Epilepsy CEO, Mark Devlin





"This is a pivotal time for those of us who represent such a large group of people and the Epilepsy Research Institute UK is exactly the right vehicle to significantly improve the lives of people living with epilepsy both in Scotland and across the United Kingdom." Epilepsy Scotland CEO, Lesslie Young











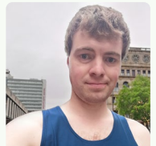


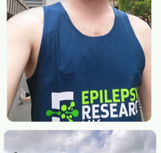


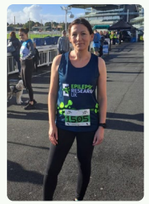












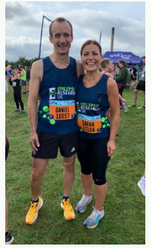




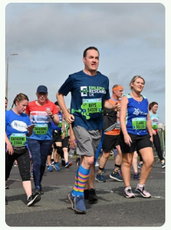
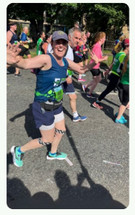
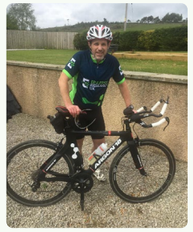


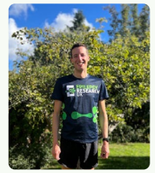


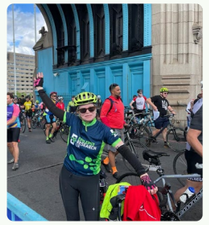


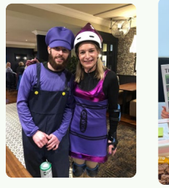


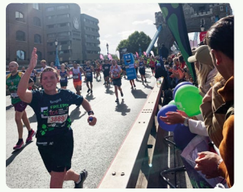


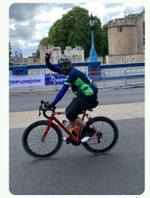




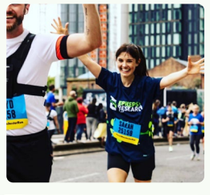




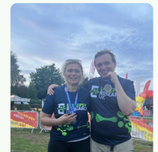
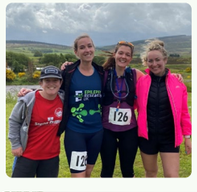



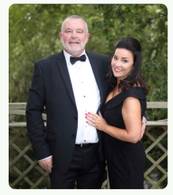














THANK YOU

Without your support, we would not have reached this pivotal point in our charity's development. From those who donated a few pounds from a charity boot sale to those who left substantial gifts to Epilepsy Research UK in their Will, we want to say a heartfelt thank you to you all.

The countless projects funded, the research breakthroughs and the creation of the Epilepsy Research Institute UK are your achievements.

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

YEAR ENDING 31ST MARCH 2023

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 2023 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
Professor Martin Elliot MB BS, MD, FRCS, FRSA (appointed June 2022)
Ms Mary Gavigan BBS MA FCA (resigned December 2022)
Dr John Hirst CBE BA FCA MCT CCBIM DSc (resigned September 2022)
Professor Tony Marson, MB ChB, MD, FRCP, FEAN (appointed March 2023)
Professor Nicholas Lench BSc, PhD, FRCPath
Professor Mark Richardson MA BMBCh MRCP PhD CCST FRCP
Mr Harry Salmon BA (resigned September 2022)
Professor Stephanie Schorge BSc, PhD, SFHEA
Ms Judith Spencer-Gregson FCA MSc
Dr Rhys Thomas BSc, MBChB, MRCP, MSc, PhD
Dr Sukhvir Wright BSc, MBBS, PhD (appointed March 2023)

President

Professor Helen Cross MB ChB PhD FRCP(UK) FRCPCH

Chief Executive

Ms Maxine Smeaton MSc PGDip MInstF

Independent auditors

Kreston Reeves, Springfield House, Springfield Road, Horsham, West Sussex, RH12 2RG

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, Ashtead Park, Ashtead, 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.

Strategy

When Epilepsy Research UK was formed in 2008, our mission was clear – to drive forward research into epilepsy. Over the last 15 years we have steadily grown our income, our research investment and our influence.

We're now in a position to award £1.7 million a year in fellowships, PhD studentships and research grants, building the capacity of epilepsy research centres throughout the UK. We currently fund over 80 projects, including clinical research to advance the medical care and management of people living with epilepsy, and lab-based scientific research investigating causes and methods for improving diagnosis, treatment and prevention of epilepsy.

Since formation our ambition to end epilepsy has never faltered. But, we know there is much more to be done. While the research we fund has led to clinical innovations and sparked further investment, progress for epilepsy has lagged behind other conditions.

Epilepsy research has been chronically underfunded. This has greatly hampered progress and is the reason why today, much like back in 2008, hundreds of thousands of people are still living with the threat of uncontrolled seizures and why 3 people every day still lose their lives.

In 2018 we highlighted the stark inequalities in neurological research funding when we published our #ALifeInterrupted – Shaping the Future of Research into Epilepsy report. Alongside this we launched a campaign to raise awareness of the underfunding of epilepsy research.

But raising awareness needed to be backed with action, and we decided to channel our ambition to end epilepsy into some big ideas to shift the dial in our favour. Our campaign called on people affected by

epilepsy to join our newly established Shape Network. This network has since become the UK's largest epilepsy patient and public involvement and engagement (PPIE) group. Today, over 350 research-interested people affected by epilepsy are now actively involved in our research assessment work and partnering on research programmes.

The following year we published our Going Further strategy, which detailed our plans to enhance epilepsy research on multiple fronts, including a greater focus on capacity-building the research environment. This programme formed the building blocks to a step change we believe could deliver our vision of a life free from epilepsy.

One of these building blocks was focusing the research community on what matters most for people with epilepsy. Last year we partnered with the James Lind Alliance (JLA) and National Institute for Health Care Research (NIHR) to identify the top ten research priorities for the epilepsy community. Throughout 2022/23 we have continued to disseminate the priorities and now researchers are using this evidence to underpin funding applications that demonstrate their research is a priority for people affected by epilepsy. This will, without doubt, lead to increased investment.

To help drive large-scale investment, this year we have rolled out the #Every1EndingEpilepsy programme. This national collaborative has brought together the epilepsy research community, epilepsy patient groups to design and delivery a research roadmap to radically advance research into epilepsy.

Our work over the last four years has led us to a huge moment in our history. In March 2023, based on our track record of being exclusively dedicated to capacity building the epilepsy research environment, we received permission from the government to become the Epilepsy Research Institute UK. The term 'Institute' is controlled by the government, and only available to those with a track record of success in their field and who operate nationally at the highest levels.

Becoming the Epilepsy Research Institute UK will provide us with the unique capability to convene and coordinate the research community. The Institute will unite everyone in a common purpose to radically advance epilepsy research. We have begun our plans for transition and look forward to an exciting and impactful year ahead.

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 with the strategy to become the Epilepsy Research Institute we will be eligible to apply for strategic investment from institutional funders. We are also holding unrestricted funds at 31 March 2023 of £3,394,171.

The reserves policy has therefore proved to be adequate to enable Epilepsy Research UK to meet its commitments without any adverse impact on our research activities.

Research grants in 2023

In 2022/23 we continued to advance knowledge of epilepsy by funding 12 new projects, spanning basic, clinical and data science studies. The awards were selected by our Scientific Advisory Committee (SAC), a panel of the UK's leading neurologists, neuroscientists and epilepsy researchers. The process is rigorous and takes nine months from first stage applications. Applications are tested, probed, interrogated, and then the SAC recommends the most promising high quality research to our Board of Trustees for funding.

The potential of this year's research awards, all focused on driving innovations in treatment and prevention of epilepsy, is huge. From targeting seizures with gene therapy to identifying brain cell mutations, our research is tackling epilepsy and its devastating impact on many fronts. Alongside funding cutting edge projects, we are also creating leaders in the field through our Fellowship Awards.

TITLE	AMOUNT	LEAD APPLICANT	INSTITUTION
Targeting seizures and cognitive comorbidities with gene therapy	£246,016	Dr Amy Richardson	UCL Queen Square Institute of Neurology
New target discovery for Tuberous Sclerosis treatment	£249,939	Dr Amanda Almacellas Barbanoj	UCL Queen Square Institute of Neurology
New therapies against epilepsy combining sleep and cellular stress genes	£245,963	Dr José Prius Mengual	University of Oxford
Adapting and evaluating a problem-solving intervention for children aged 9-12 years with epilepsy	£155,584	Prof Anna Adlam	University of Exeter
Can metabolism of lysine be targeted to treat epilepsy in tuberous sclerosis complex (TSC)?	£174,495	Dr Felix Chan	Aston University
Do babies with genetic epilepsy have more excitable neurons?	£163,444	Dr Amy McTague	UCL Great Ormond Street Institute of Child Health
How safe are anti-seizure medicines used in pregnancy?	£173,842	Dr Anita McGrogan	University of Bath
Investigating anti-seizure medications and breastfeeding using the UK and Ireland Epilepsy and Pregnancy Register	£29,969	Dr John Craig	Belfast Health & Social Care Trust
How can the new generation of MEG machines help patients awaiting epilepsy surgery?	£29,583	Dr Caroline Witton	Aston University
Identification of brain cell mutations in focal epilepsy	£29,988	Prof Maria Thom	UCL Queen Square Institute of Neurology
Using Natural Language AI to identify predictors of refractory epilepsy in NHS Electronic Health Records	£199,595	Prof Mark Richardson	King's College London
Using large-scale data and artificial intelligence for refractory epilepsy research	£50,000	Dr Owen Pickrell	Swansea University
Total grants awarded	**£1,748,418**		

We are currently funding 80 projects in total, 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 £5.94 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 400 journal publications have resulted from ERUK grants during the 2009 – 2023 period, 93 of which were in high impact journals (IF of 10 or above) such as Brain, Nature and Science. 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 4,000 times.

Fundraising performance in 2022/23

The overall incoming resources from fundraising and trading activities during 2022/23 were £2,508,370 an increase in income of 102% compared to the previous year. This was largely boosted by grants of £1,284,839 for existing early career researchers from BEIS in recognition of the losses experienced by medical research as a result of Covid-19. Legacy income in the year was £928,728. 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, 100% of our fundraised income primarily came from our community of supporters and trusts and foundations. 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 in-person events are beginning to return to normal, 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 2022/23 our overall incoming resources were £3,605,370 and the costs of raising funds were £173,303 leaving £3,432,067 available for charitable activities. This was an increase in net income of £753,294 compared to the previous year. The total spent on charitable activities was £2,485,123.

This year we were fortunate in receiving further grants of £1,284,839 from the government to compensate for delays to research for early career researchers. We also had exceptional levels of legacy income. 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 2023 of £1,758,950 an increase of 12% over 2022. 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 2023 will be utilised to try to maintain research grants at a similar level for the foreseeable future.

Bank balances of £3,557,081 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. There was significant volatility in investment performance during the year following overseas hostilities and the impact of rising interest rates on bond returns. There was an unrealised loss on investment values within the year of £263,090.

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, Epilepsy Research UK is planning to improve the 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. There are two key subcomittees; the Nominations Committee and the Finance and Audit Committee. 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 controlling, running and operating the Charity on a day-to-day basis. All directors give their time freely and no director received remuneration in the year. Details of directors' expenses and related party transactions are disclosed in note 12 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 2022/23 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 cost of living crisis.

Risk 2: Inadequate 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 2023 are £2,494,171 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

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

We have audited the financial statements of Epilepsy Research UK (the Charity) for the year ended 31st March 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the Charity's trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Opinion on financial statements

We have audited the financial statements of Epilepsy Research UK ("the charitable company") for the year ended 31 March 2023 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a 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).

In our opinion the financial statements:
• give a true and fair view of the state of the charitable company's affairs as at 31 March 2023, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
• have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
• have been prepared in accordance with the requirements of the Companies Act 2006.

Basis 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 charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.
Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for

a period of at least twelve months from when the financial statements are authorised for issue.
Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the Trustees' Annual Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the Annual Report. 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. 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 course of 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 this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:
• the information given in the Trustees' Annual Report (incorporating the Strategic Report and the Directors' Report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
• the Strategic Report and the Directors' Report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Strategic Report and the Directors' Report.
We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:
• adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
• the financial statements are not in agreement with the accounting records and returns; or
• certain disclosures of directors' remuneration specified by law are not made; or
• we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

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

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conduct in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatement can arise from fraud or error and are consider 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.

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

Capability of the audit in detecting irregularities, including fraud

Based on our understanding of the Charity, and through discussion with the directors and other management (as required by auditing standards), we identified that the principal risks of non-compliance with laws and regulations related to GDPR and employment law. We considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006. We communicated identified laws and regulations throughout our team and remained alert to any indications of non-compliance throughout the audit. We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to posting inappropriate journal entries to increase revenue or reduce expenditure, the recognition of grants payable and revenue recognition. Audit procedures performed by the engagement team included:
• Discussions with management and assessment of known or suspected instances of non-compliance with laws and regulations and fraud, and review of the reports made by management; and
• Assessment of identified fraud risk factors; and
• Holding discussions with appropriate personnel to gain further insight into the control systems implemented, and the risk of irregularity; and
• Performing analytical procedures to identify any unusual or unexpected relationships, including related party transactions, that may indicate risks of material misstatement due to fraud; and
• Confirmation of related parties with management, and review of transactions throughout the period to identify any previously undisclosed transactions with related parties outside the normal course of business; and
• Reading minutes of meetings of those charged with governance and reviewing correspondence with relevant tax and regulatory authorities; and
• Verifying the year-end cash at bank balances to online banking portals to verify accuracy; and
• Review of significant and unusual transactions and evaluation of the underlying financial rationale supporting the transactions; and
• Identifying and testing journal entries, in particular any manual entries made at the year end for financial statement preparation.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial

statements, as we will be less likely to become aware of instances of non-compliance.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment 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 charitable company's internal control.

• Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.

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

• Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation (ie. gives a true and fair view).

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

Use of our report

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

James Peach BA FCA (Senior Statutory Auditor)
For and on behalf of Kreston Reeves LLP
Chartered Accountants and Statutory Auditor
Horsham
Date:

Statement of Financial Activities
for the year ended 31st March 2023

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Total Funds 2022 Restated (Note 2)
Income from:					
Donations and legacies	3	1,666,313	300,752	**1,967,065**	2,741,712
Grants	4	-	1,451,840	**1,451,840**	-
Other trading activities	5	18,193	-	**18,193**	25,592
Investments	6	168,272	-	**168,272**	86,119
Total Income		**1,852,778**	**1,752,592**	**3,605,370**	**2,853,423**
Expenditure on:					
Cost of raising funds					
Raising Funds	7	173,303	-	**173,303**	174,650
Charitable activities					
Research grants committed	8	1,705,986	-	**1,705,986**	1,439,264
Other research activities	9	705,613	73,524	**779,137**	519,239
Total charitable expenditure		2,411,599	73,524	**2,485,123**	1,958,503
Total expenditure		**2,584,902**	**73,524**	**2,658,426**	**2,133,153**
Net unrealised gains / (losses) on investments		(263,090)	-	**(263,090)**	20,557
Net income/(expenditure) for the year		(995,214)	1,679,068	**683,854**	740,827
Transfers between funds	16	1,750,897	(1,750,897)	-	-
Net movement in funds for the year		**755,683**	**(71,829)**	**683,854**	**740,827**
Reconciliation of funds:					
Total funds brought forward on 1 April		2,638,488	73,242	**2,711,730**	1,970,903
Total funds carried forward at 31 March	16-18	**3,394,171**	**1,413**	**3,395,584**	**2,711,730**

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 17 to 30 form part of these financial statements.

Balance Sheet
at 31st March 2023

	Note	2023 £	2022 £
Fixed assets			
Investments	13	**3,740,842**	3,897,165
		3,740,842	3,897,165
Current assets			
Debtors	14	**1,868,069**	740,075
Cash at bank and in hand		**3,557,081**	3,026,035
		5,425,150	**3,766,110**
Creditors: amounts falling due within one year	15	**(2,926,568)**	(2,007,029)
Net current assets		**2,498,582**	1,759,081
Total assets less current liabilities		**6,239,424**	5,656,246
Creditors: Amounts falling due within one year	15	**(2,843,840)**	(2,944,516)
Total net assets		**3,395,584**	**2,711,730**
The funds of the charity			
Unrestricted funds	16		
Designated funds		**2,494,171**	1,738,488
General fund		**900,000**	900,000
		3,394,171	2,638,488
Restricted funds	17	**1,413**	73,242
Total charity funds		**3,395,584**	**2,711,730**

The financial statements were approved by the Board of Trustees on 13 September 2023 and signed on its behalf by:

Prof Matthew Walker
Chair

Judith Spencer-Gregson FCA
Treasurer

Registered company number: 4873718
Registered charity number: 1100394

The notes on pages 17 to 30 form part of these financial statements.

Statement of Cash Flows
for the year ended 31st March 2023

	2023 £	2022 £
Cash inflow from operating activities	**469,541**	1,105,381
Cash flows from investing activities		
Sale of investments	**-**	28
Net purchase of investments	**-**	(1,500,000)
Income reinvested	**(106,764)**	(65,030)
Dividends and interest received	**168,269**	86,119
Net cash inflow/(outflow) from investing activities	**61,505**	(1,478,883)
Increase/(decrease) in cash and cash equivalents in the year	**531,046**	**(373,502)**
Cash and cash equivalents at the beginning of the year	**3,026,035**	3,399,537
Cash and cash equivalents at the end of the year	**3,557,081**	**3,026,035**

Reconciliation of net movement in funds to net cash flow from operating activities

Net movement in funds	**683.854**	740,827
Deduct investment income shown in investing activities	**(168,272)**	(86,119)
Deduct investment gain/add (loss)	**263,090**	(20,557)
(Increase)/decrease in debtors	**(1,127,994)**	(131,443)
Increase/ (decrease) in creditors due within one year	**919,539**	50,338
Increase/(decrease) in creditors due after more than one year	**100,676**	552,335
Net cash from operating activities	**469,541**	1,105,381

Analysis of cash and cash equivalents

Cash deposits	**2,852,508**	2,835,675
Cash at bank	**704,573**	190,360
Net Cash from/used in operating activities	**3,557,081**	3,026,035

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

Analysis of changes in net debt

	As at 31 Mar 22	Cashflows	As at 31 Mar 23
Cash deposits and cash at bank	3,026,035	531,046	3,557,081

There were no overdrafts, loans or finance lease obligations within the period

Notes
forming part of the financial statements for the year ending 31st March 2023

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 2019) – 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 Correction of a prior period error

By their very nature research projects may be completed without the full utilisation of the relevant grant awarded, or, on occasion, the research may not be undertaken, and the grant withdrawn. In both of these instances any remaining funds will be written back for the funding of other successful grant applications.

These write backs should be offset against charitable expenditure research grants committed, where the grant expenditure was originally recognised.

For the year to 31 March 2022 these write backs amounted to £133,585 and were incorrectly identified as income within the Statement of Financial Activities. This has been corrected in the prior year comparatives of the accounts for the year ending 31 March 2023, which has resulted in the following restatements for 2022:

Total income has been reduced by £133,585 from £2,987,008 to £2,853,423
Research grants committed expenditure has been reduced by £133,585 from £1,572,849 to £1,439,264
Total charitable expenditure has been reduced by £133,585 from £2,092,088 to £1,958,503
Total expenditure has been reduced by £133,585 from £2,266,738 to £2,133,153
All other figures for the year to 31 March 2022 remain as previously stated.

For the year to 31 March 2023, grant write backs amounted to £52,964 and have correctly been offset against research grants committed within charitable activities expenditure.

3 Donations and Legacies

	Unrestricted Funds £	Restricted Funds £	Total 2023 £	Total 2022 £
Charitable trusts	90,390	118,700	209,090	139,083
In memoriam donations	87,519	-	87,519	88,452
Other donations	293,546	181,955	475,501	766,179
Fundraising events	266,130	97	266,227	225,162
Legacies	928,728	-	928,728	1,522,836
	1,666,313	300,752	1,967,065	2,741,712

Donations and Legacies 2022

	Unrestricted Funds £	Restricted Funds £	Total 2022 £
Charitable trusts	44,483	94,600	139,083
In memoriam donations	88,452	-	88,452
Other donations	267,448	498,731	766,179
Fundraising events	225,162	-	225,162
Legacies	1,522,836	-	1,522,836
	2,148,381	593,331	2,741,712

Income from fundraising events arises from events organised by the charity and its supporters.
Online advertising to the value of £95,403 (2022: £78,821) 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.

4 Grants received

	Unrestricted Funds £	Restricted Funds £	Total 2023 £	Unrestricted Total 2022 £
BEIS COVID-19 charity support fund	-	1,451,840	1,451,840	-

5 Other Trading Activities

	Unrestricted Funds £	Restricted Funds £	Total 2023 £	Unrestricted Total 2022 £
Sale of christmas cards	17,593	-	17,593	22,592
Fees charged	600	-	600	3,000
	18,193	-	18,193	25,592

6 Investment Income

	Unrestricted Funds £	Restricted Funds £	Total 2023 £	Unrestricted Total 2022 £
Realised gain on investments	3	-	3	-
Dividend & investment income	150,461	-	150,461	82,790
Interest on deposits	17,808	-	17,808	3,329
	168,272	-	168,272	86,119

7 Costs of generating funds

	Unrestricted Funds £	Restricted Funds £	Total 2023 £	Unrestricted Total 2022 £
Direct fundraising	100,482	-	100,482	63,269
Staff costs	49,597	-	49,597	89,215
Other overhead expenses	11,026	-	11,026	15,537
Governance costs	12,198	-	12,198	6,629
	173,303	-	173,303	174,650

8 Research Grants Committed

	2023 £	2022 £
Committed as at 31 March 2022	4,913,045	4,298,279
Authorised during year (see Trustees' report)	1,758,950	1,572,849
No longer required	(52,964)	(133,585)
Paid in year	(1,009,520)	(824,498)
Committed as at 31 March 2023	5,609,511	4,913,045

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

9 Other Research Activities

	Unrestricted Funds £	Restricted Funds £	Total 2023 £	Total 2022 £
Staff costs	359,300	45,526	404,826	304,404
Director of #Every1EndingEpilepsy	12,889	-	12,889	-
Research meetings, events & activities	38,242	17,608	55,850	12,571
Research awards & prizes	-	500	500	736
Research dissemination & communication	115,528	-	115,528	123,569
Overhead expenses	80,099	9,890	89,989	55,346
Governance costs	99,555	-	99,555	22,613
	705,613	73,524	779,137	519,239

Other Research Activities 2022

	Unrestricted Funds £	Restricted Funds £	Total 2022 £
Staff costs	268,963	35,441	304,404
Director of #Every1EndingEpilepsy	-	-	-
Research meetings, events & activities	12,571	-	12,571
Research awards & prizes	236	500	736
Research dissemination & communication	118,034	5,535	123,569
Overhead expenses	48,704	6,642	55,346
Governance costs	22,613	-	22,613
	471,121	48,118	519,239

10 Support and Governance costs

	Support Costs £	Governance Costs £	Total 2023 £	Total 2022 £
Staff costs	-	34,712	34,712	10,729
Other staff costs	45,828	-	45,828	14,914
Office rent & facilities	22,376	-	22,376	20,865
Office running costs	13,341	-	13,341	12,245
IT & bank charges	27,191	-	27,191	22,859
Investment fees	-	39,197	39,197	18,367
Audit	-	15,986	15,986	5,562
Trustee meetings & expenses	-	6,950	6,950	2,912
Legal & professional fees	-	7,187	7,187	2,400
	108,736	104,032	212,768	110,853
Basis of allocation				
Allocated to fundraising costs	11,868	11,355	23,223	10.91%
Allocated to charitable activities	96,868	92,677	189,545	89.09%
	108,736	104,032	212,768	100.00%

Support and Governance costs 2022

		Support Costs £	Governance Costs £	Total 2022 £
Staff costs		-	10,729	10,729
Other staff costs		14,914	-	14,914
Office rent and facilities		20,865	-	20,865
Office running costs		12,245	-	12,245
IT and bank charges		22,859	-	22,859
Investment fees		-	18,367	18,367
Audit		-	5,562	5,562
Trustee meetings & expenses		-	2,912	2,912
Legal & professional fees		-	2,400	2,400
		70,883	39,970	110,853
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%

11 Total auditor's remuneration

	2023 £	2022 £
Remuneration in relation to the audit of the finanical statements	15,986	5,562
Remuneration for other services: payroll processing	1,470	846

12 Staff Costs

	2023 £	2022 £
Salaries	418,781	346,535
Social security costs	42,098	33,743
Pension costs	28,257	13,341
	489,136	393,619

Employees receiving salaries within the following bands:	2023	2022
£70,001 to £80,000	-	1
£80,001 to £90,000	1	-

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

	2023	2022
Charitable activities	8.29	5.99
Fundraising	0.98	1.73
Governance	0.78	0.13
	10.05	7.85

Epilepsy Research UK incurred total Trustee and key management personnel remuneration costs during the period of £100,278 (2022: £93,819).
The Trustees do not receive any remuneration for their duties and during the year received expenses of £1,999 for travelling to meetings (2022: £683).
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.

13 Investments

	2023 £	2022 £
Market value 1 April 2022	3,897,165	2,311,606
Acquisitions	-	1,500,000
Sales at market value	-	(28)
Investment charges	(43,697)	(18,367)
Income reinvested	150,461	83,397
	4,003,929	3,876,608
Net gain/(loss) realised	3	-
Net gain/(loss) unrealised	(263,090)	20,557
Market value 31 March 2023	3,740,842	3,897,165
Analysis of investments		
Quoted Charity Common Investment funds	3,617,408	3,380,546
Medium and long term	123,434	516,619
Cash on deposit	3,740,842	3,897,165

14 Debtors

	2023 £	2022 £
Gift Aid recoverable	7,486	6,633
Prepayments & accrued income	1,860,583	733,442
	1,868,069	740,075

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.

15 Liabilities

	2023 £	2022 £
Research grants not yet claimed	2,765,671	1,968,529
Accruals	38,790	13,589
Other creditors	122,107	24,911
Due within 12 months	2,926,568	2,007,029
Research grants due after 12 months	2,843,840	2,944,516
	5,770,408	4,951,545

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

16 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 funds represents money set aside by the Trustees for future research grants and for the #Every1EndingEpilepsy, a programme with the vision to radically advance the treatment and prevention of epilepsy.

	Designated Funds		General Fund	Total 2023
	Research Fund £	#Every1Ending Epilepsy £	£	£
Balance as at 1 April 2022	1,388,488	350,000	900,000	2,638,488
Net incoming resources	-	-	755,683	755,683
Transfer between funds	825,465	(69,782)	(755,683)	-
Balance as at 31 March 2023	2,213,953	280,218	900,000	3,394,171

Unrestricted Funds 2022

	Designated Funds		General Fund	Total 2022
	Research Fund £	#Every1Ending Epilepsy £	£	£
Balance as at 1 April 2021	1,042,684	-	900,859	1.943.543
Net incoming resources	-	-	694,945	694.945
Transfer between funds	345,804	350,000	(695,804)	-
Balance as at 31 March 2022	1,388,488	350,000	900.000	2,638,488

17 Restricted Funds

	1 April 2022 £	Incoming Resources £	Resources Expended £	31 March 2023 £
Research grants	-	1,750,897	(1750,897)	-
Shape Network	67,382	1,695	(69,077)	-
Celine Newman bursary	5,860	-	(4,447)	1,413
	73,242	1,752,592	(1,824,421)	1,413

Epilepsy Research UK supports a wide range of research, from experimental studies of epilepsy, including laboratory research of the cellular and molecular mechanisms of epilepsy, to novel diagnostics and treatments for the clinical management of people living with epilepsy. 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 2022

	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
	27,360	593,331	(547,449)	73,242

18 Analysis of Net Assets between Funds

	Unrestricted Funds 2023 £	Restricted Funds 2023 £	Total Funds 2023 £
Total assets	9,164,579	1,413	9,165,992
Current liabilities	(2,926,568)	-	(2,926,568)
Creditors falling due after more than 1 year	(2,843,840)	-	(2,843,840)
	3,394,171	1,413	3,395,584

Analysis of Net Assets between Funds 2022

	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)
	2,638,488	73,242	2,711,730

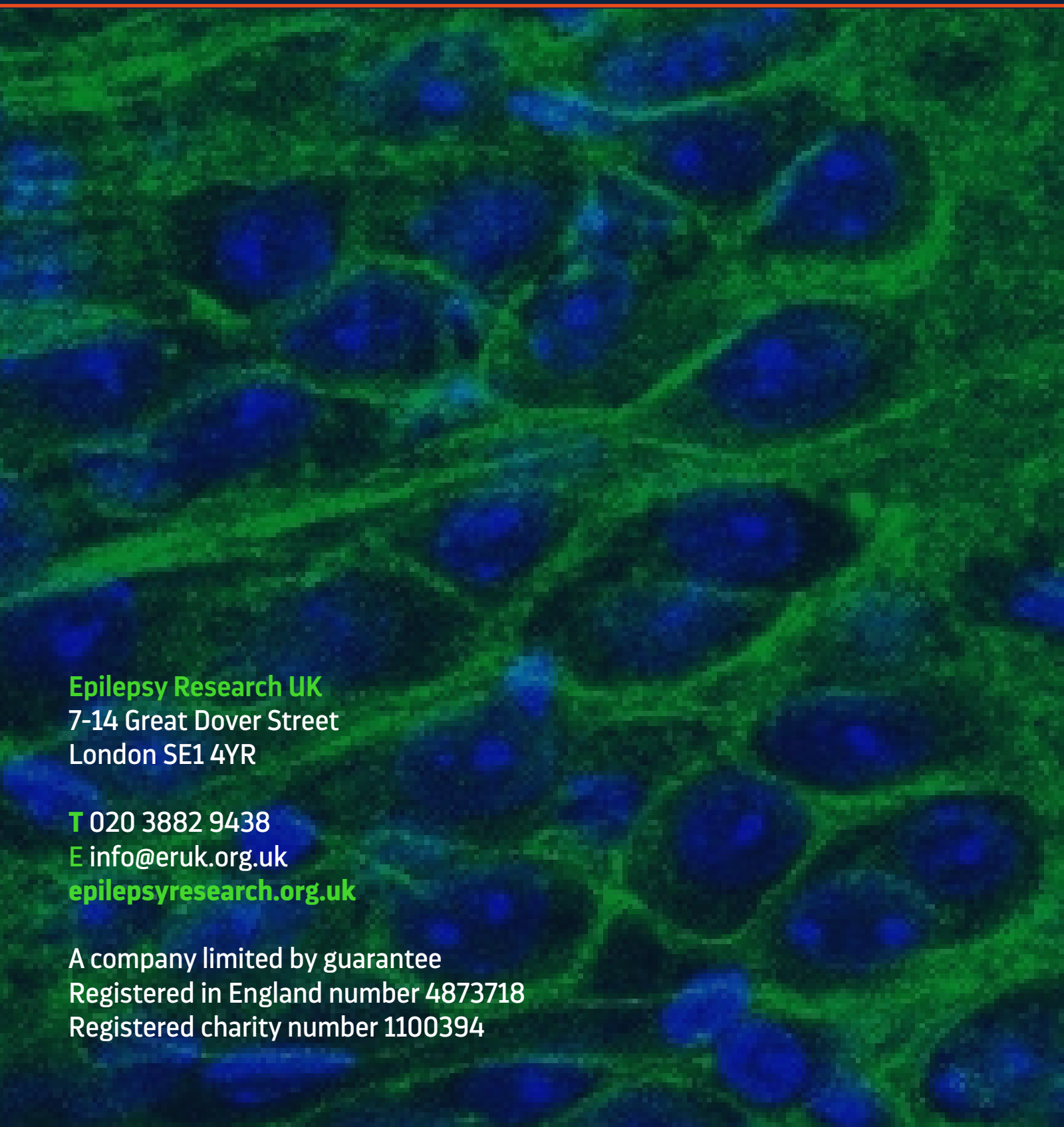
19 Related Party Transactions

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 Commitee (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. A co-funded award with Angelini Pharma of £200k was made to Professor Mark Richardson. The funding split was £170k from Angelini Pharma and £30k from Epilepsy Research UK. No grants were awarded in 2022 to Trustees, although some had connections to the institutions.

20 Statement of Financial Activity for the year ended 31 March 2022 (prior year) (Including the Income & Expenditure Account)

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 Restated £
Income from:				
Donations and legacies	2	2,148,381	593,331	2,741,712
Other trading activities	3	25,592	-	25,592
Investments	4	86,119	-	86,119
Total Income		**2,260,092**	**593,331**	**2,853,423**
Expenditure on:				
Raising Funds	5	174,650	-	174,650
Charitable Activities:				
Research grants committed	6	1,439,264	-	1,439,264
Other charitable activities	7	471,121	48,118	519,239
Total Charitable Activities		1,910,385	48,118	1,958,503
Total Expenditure	10	**2,085,035**	**48,118**	**2,133,153**
Net unrealised Gains/(Losses) on investments		20,557	-	20,557
Net Income/(Expenditure) for the year		195,614	545,213	740,827
Transfers between funds	16	499,331	(499,331)	-
Net Movement in Funds for the year		**694,945**	**45,882**	**740,827**
Reconciliation of Funds:				
Total funds brought forward on 1 April 2019		1,943,543	27,360	1,970,903
Total funds carried forward at 31 March 2020	17	**2,638,488**	**73,242**	**2,711,730**

EPILEPSY RESEARCH UK



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A company limited by guarantee
Registered in England number 4873718
Registered charity number 1100394

EPILEPSY RESEARCH INSTITUTE UK

England & Wales - Charity number 1100394

Accounts

EPILEPSY RESEARCH UK

EPILEPSY RESEARCH - ARE WE AT A TIPPING POINT?

Annual Review 2021/22



2022

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."



CONTENTS

Page 6 A message from our Chair & CEO

Page 8 Research in numbers

Page 10 A year in research

Page 18 Gathering the evidence to drive change

Page 22 Connecting researchers with people affected by epilepsy

Page 26 Stronger together - building partnerships and collaborations

Page 28 Are we at tipping point?

Page 34 THANK YOU

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

Page 2 Reference and administrative details

Page 3 Objectives and activities

Page 13 Independent auditor's report

Page 16 Statement of financial activities

Page 17 Balance sheet

Page 18 Statement of cash flows

Page 19 Notes to the financial statements

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 NHIR. 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**.

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 #Every1EndingEpilsepy 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 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.



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



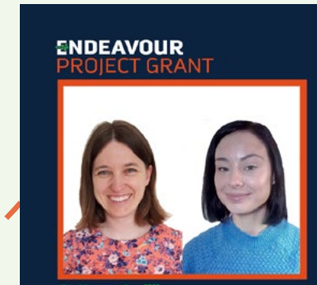
Dr Sophie Adler
University College London
Multi-centre Epilepsy Lesion Detection Project: a collaborative cohort for the analysis of focal epilepsies

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 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

ENDEAVOUR PROJECT GRANT



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

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.

EPILEPSY RESEARCH UK

ASSOCIATION OF BRITISH NEUROLOGISTS

Stroke Association

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



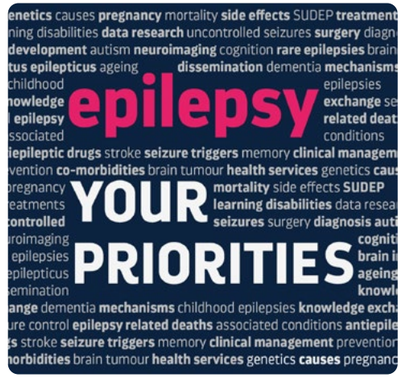
Dr Faye McLeod
Newcastle University

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%.

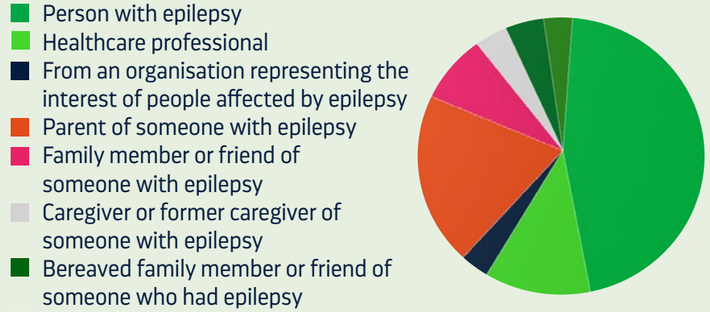


"The unified voice of the epilepsy community will be an essential tool in influencing government, and institutional and strategic funders to invest more in this chronically underfunded area of research and will support our own plans for sustainability. The rigorous approach we have taken will provide 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?



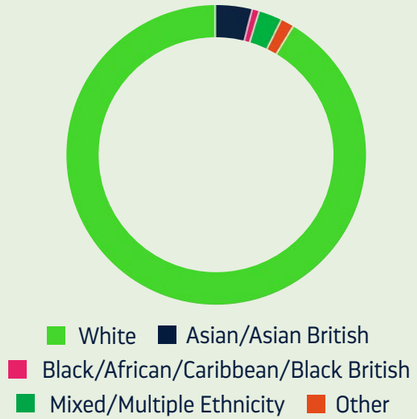
WHERE DO YOU LIVE?



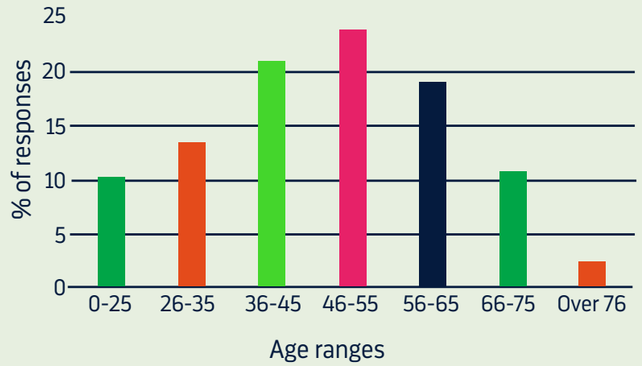
GENDER



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 'ALifeInterrupted' 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.



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.



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 Brainathalon 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
#Every1EndingEpilsepy 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.

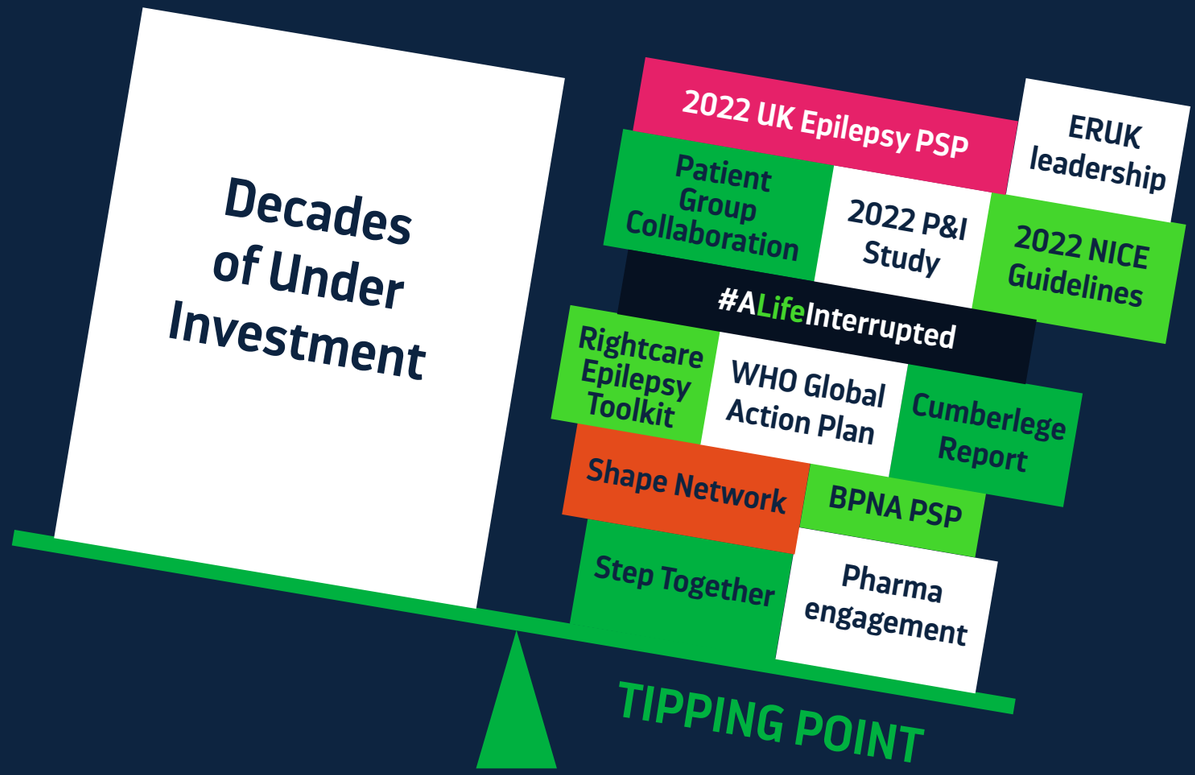
The World Health Organisation (WHO) Intersectoral Global Action Plan (IGAP) on Epilepsy
Approved in May, the IGAP has the potential to bring about significant change in policy and practise around the world. It covers a 10-year period from 2022-31 and will build on existing global resolutions, commitments 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.

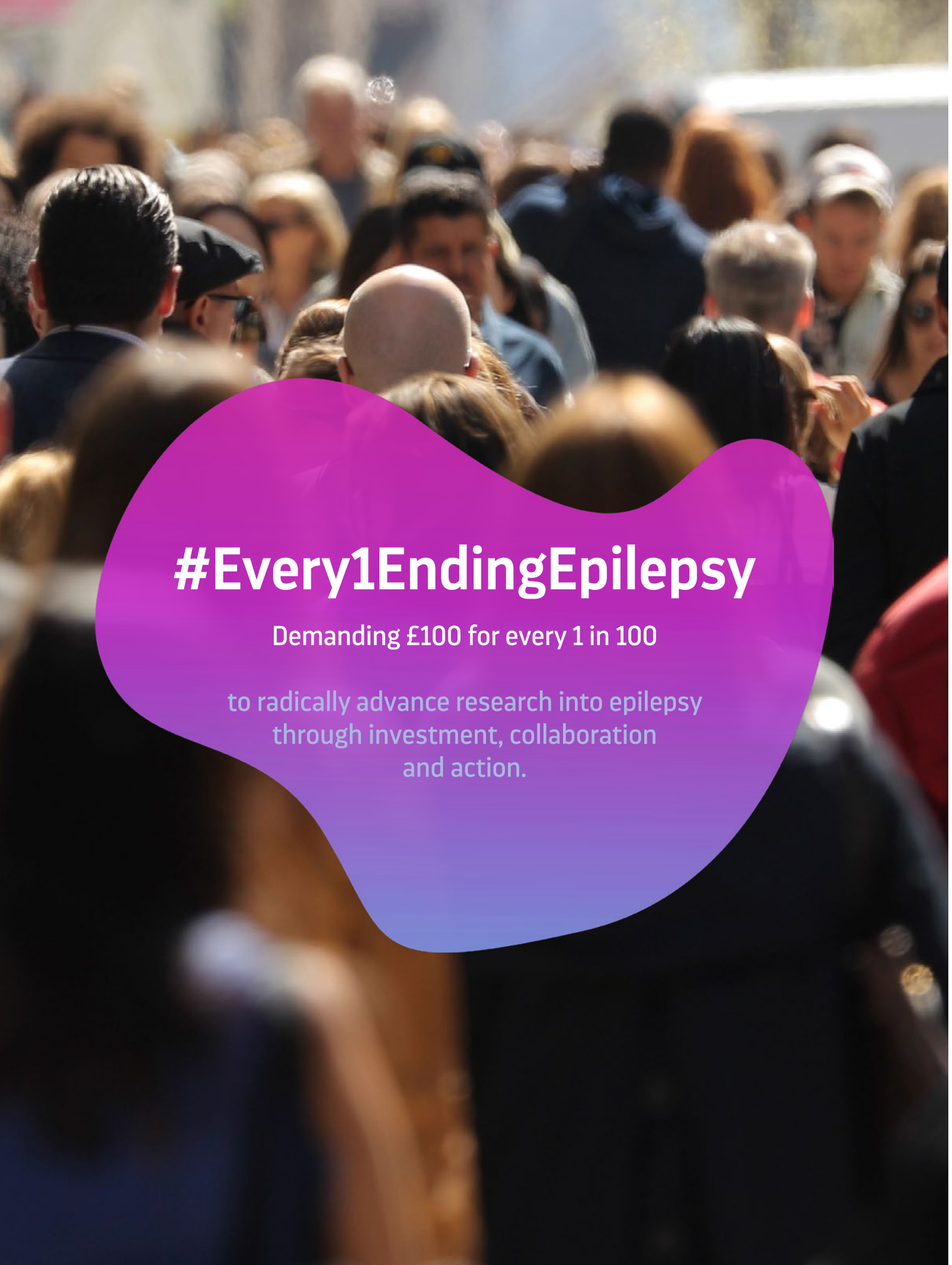
Governments around the world are now tasked with responding to the recommendations. These IGAP recommendations, together with new NICE Guidelines and the results of the UK Epilepsy Priority Setting Partnership, will shape future research for the next generation

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 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, #Every1EndingEpilsepy 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, #Every1EndingEpilsepy programme director



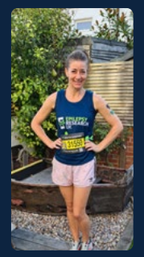
#Every1EndingEpilepsy will raise public awareness of the impact of epilepsy and demonstrate how, by working collaboratively, we can bring about a radical change within a generation



"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

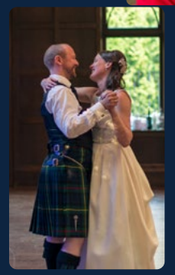
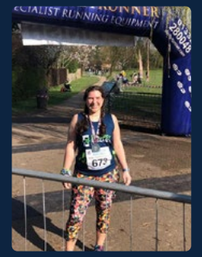
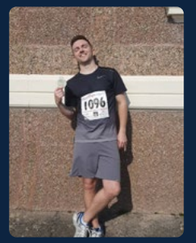
Once again, everything we've been able to do this year is because of our amazing supporters. Thank you. Whether from regular monthly donations, gifts in Wills or fundraising challenges, please know that your efforts have a direct impact on researchers' ability to stop the devastation caused by epilepsy.

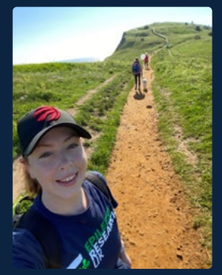






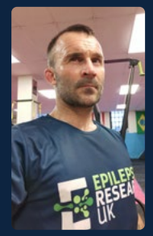






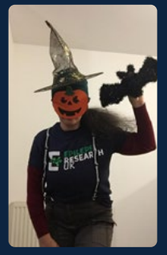
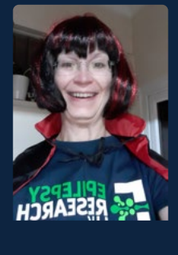




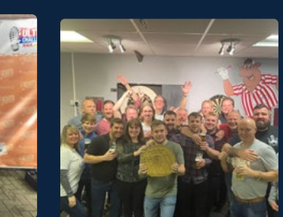


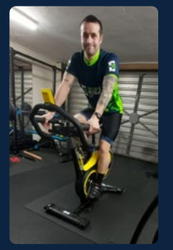


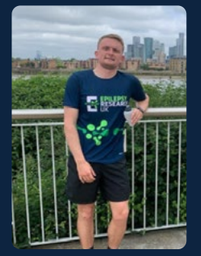












WE STILL NEED YOU

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

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	1,105,381	414,578
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		(1,478,883)	22,456
(Decrease)/Increase in Cash and Cash Equivalents in the Year		**(373,502)**	**437,034**
Cash and Cash Equivalents at the Beginning of the Year		3,399,537	2,962,503
Cash and Cash Equivalents at the End of the Year		**3,026,035**	**3,399,537**

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
	2,148,381	593,331	2,741,712	1,112,408

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
	1,020,408	92,000	1,112,408

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	-
	25,592	-	25,592	16,495

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
	86,119	-	86,119	64,741

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
		174,650	-	174,650	158,935

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: wwwepilepsyreearch.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
	393,619	384,923

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
	7.85	7.90

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
	3,876,608	2,057,853
Net gain/(loss) realised	-	664
Net gain/(loss) unrealised	20,557	253,089
Market value 31 March 2022	3,897,165	2,311,606
Analysis of investments		
Quoted Charity Common Investment funds	3,380,546	2,294,209
Medium and long term	516,619	17,397
	3,897,165	2,311,606

12 Debtors

	2022 £	2021 £
Gift Aid recoverable	6,633	20,831
Prepayments & accrued income	733,442	587,801
	740,075	608,632

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
	27,360	593,331	(547,449)	73,242

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	
	£499,331	

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
	6,960	92,000	(71,600)	27,360

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)
	2,638,488	73,242	2,711,730

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)
	1,943,543	27,360	1,970,903

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.

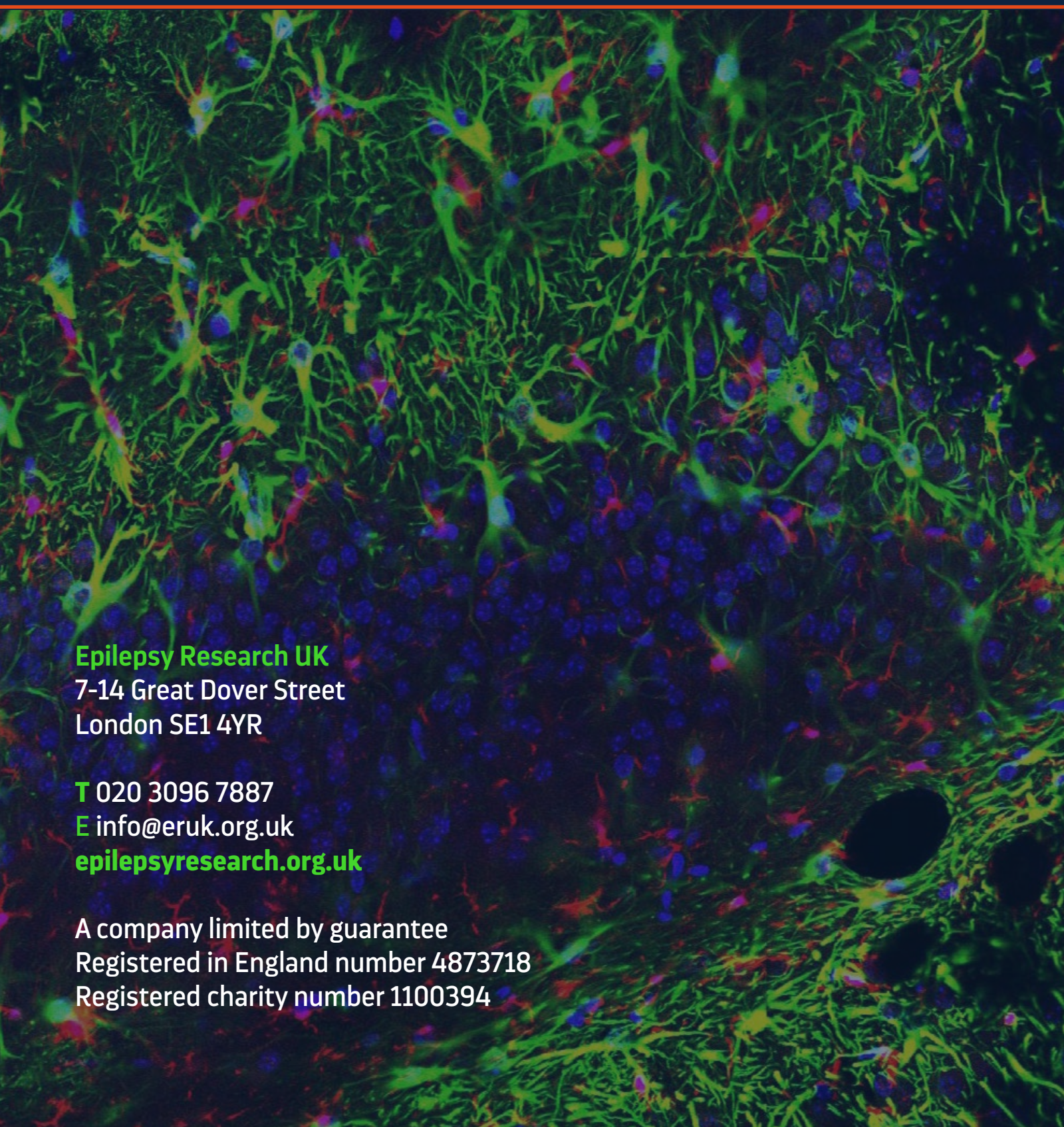
19 Reconciliation of Net Movement in Funds to Net Cash Flow from Operating Activities

	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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A company limited by guarantee
Registered in England number 4873718
Registered charity number 1100394

EPILEPSY RESEARCH INSTITUTE UK

England & Wales - Charity number 1100394

Accounts

EPILEPSY RESEARCH UK

A YEAR OF RESILIENCE, RECOVERY AND RENEWAL

Annual Review 2020/21





600,000

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

180,000

have NO treatment options and live with uncontrolled seizures

600

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

GOING FURTHER THAN EVER BEFORE

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

We will go further than ever to transform epilepsy research.

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

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

The strength of our community

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

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

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

CONTENTS

Page 6 Research grants in 2020/21

Page 8 Shining a light on the funding problem

Page 10 Our response to COVID-19

Page 16 Recovery and renewal

Page 22 Going further

Page 26 Because of you

Page 27 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

Page 28 Reference and administrative details

Page 29 Objectives and activities

Page 37 Independent auditor's report

Page 40 Statement of financial activities

Page 41 Balance sheet

Page 42 Statement of cash flows

Page 43 Notes to the financial statements

MESSAGE FROM OUR CHAIR & CEO





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

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

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

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

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

We've launched virtual fundraising events so our amazing supporters could stay connected. We developed an online programme of events to continue the information sharing and collaborations vital for future breakthroughs. And, we rapidly put plans in place to protect our researchers from the damaging impact of COVID-19, by increasing funding and extending deadlines.

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

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

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

Thank you.

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

EPILEPSY RESEARCH UK IS FUNDING...

18 NEW STUDIES THIS YEAR

60 RESEARCHERS

58 RESEARCH PROJECTS IN TOTAL



Research grants in 2020/21

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

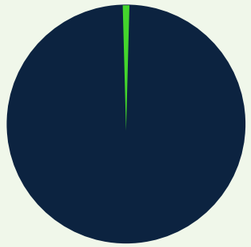
PRINCIPAL INVESTIGATOR, INSTITUTION	TITLE	AMOUNT
Professor Markus Reuber University of Sheffield	Comparing interactions in remote and face-to-face seizure clinic consultations	£49,979
Professor Sameer Zuberi University of Glasgow	Evaluation of a new clinical service to allow video sharing and remote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

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

SHINING A LIGHT ON THE FUNDING PROBLEM

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

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



SHAPE NETWORK

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

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

Capacity building epilepsy research by providing a national PPI service

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

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



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





OUR RESPONSE TO COVID-19



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

OUR RESPONSE TO COVID-19

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

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



1. SUPPORT INNOVATIONS IN HEALTHCARE

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

Prof Markus Reuber
£49,979



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

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

Prof Sameer Zuberi
£49,726



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

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

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

Dr Rhys Thomas
£49,618



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

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

2. PROTECT OUR RESEARCHERS

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

£78,000
was invested in existing projects to ensure their recovery following the pandemic



CONTINUING IMPORTANT WORK ON ABSENCE SEIZURES

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

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

RESEARCHING THE LINKS BETWEEN SEIZURES AND MIGRAINES

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



3. SECURE OUR INCOME

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

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



4. SHARE INFORMATION

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

RESEARCH ROUNDTABLE

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



RESEARCH BLOG

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



MOST POPULAR BLOG OF 2020

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

OVER 10,000
WEBINAR VIEWS*

OVER 13,000
BLOG VIEWS

*since launching our series at the end of May 2020

RECOVERY AND RENEWAL



Dr Vincent Magloire
Epilepsy Research UK Emerging Leader Fellow 2019

RECOVERY AND RENEWAL
CAPACITY BUILDING EPILEPSY RESEARCH FOR THE FUTURE

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

We awarded **£1.32m** in research funding → this investment has funded **18** new studies → involving over **60** researchers

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

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

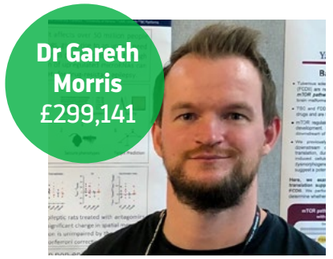
We took the difficult decision not to fund the Explore Pilot and Endeavour Project studies in the 2020/21 grant round and instead focused our investment on our ERUK Emerging Leader Fellowship Awards and our Doctoral Training Centre Grant scheme to build future generations into international leaders.

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



FELLOWSHIP AWARD

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



EPILEPSY RESEARCH UK EMERGING LEADER FELLOWSHIP AWARD

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

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

ERUK-FUNDED RESEARCH MAKING AN IMPACT

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

ERUK-FUNDED RESEARCH MAKING AN IMPACT

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



EPILEPSY RESEARCH UK & YOUNG EPILEPSY FELLOWSHIP AWARD

Wellcome Centre for Human Neuroimaging
University College London
Dr Tim Tierney

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

DOCTORAL TRAINING CENTRE GRANT SCHEME

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

EPILEPSY RESEARCH UK & NEWCASTLE UNIVERSITY DOCTORAL TRAINING CENTRE

£250,000 with matched funding from Newcastle University

Professor Andrew Trevelyan, Dr Rhys Thomas

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

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



Professor Andrew Trevelyan



Dr Rhys Thomas



Professor Richard Chin



Professor Cathy Abbott

EPILEPSY RESEARCH UK & EDINBURGH UNIVERSITY DOCTORAL TRAINING CENTRE

£250,000 with matched funding from Edinburgh University

Professor Richard Chin, Professor Cathy Abbott

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

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

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

FINAL REPORT FROM OUR 2018 EMERGING LEADER FELLOWSHIP AWARD

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

ERUK-FUNDED RESEARCH MAKING AN IMPACT

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



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

Mr Ashan Jayasekera



THE COIN STUDY

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

GOING FURTHER



Amanda, John and children
Epilepsy Research UK supporters

GOING FURTHER

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



OUR VISION: A LIFE FREE FROM EPILEPSY

OUR PURPOSE: DRIVING AND ENABLING LIFE CHANGING LIFE SAVING RESEARCH INTO EPILEPSY

OUR PRORITIES:

- Promote, encourage and fund research into the causes, and diagnosis of epilepsy and clinical management of people with epilepsy and associated conditions.
- Develop the next generation of epilepsy researchers and capacity build the epilepsy research environment.
- Accelerate innovations for people with epilepsy by supporting and commissioning research that will influence clinical practice and health policy.

VALUES: IMPACTFUL RIGOROUS INNOVATIVE COLLABORATIVE

THREE PRIORITY AREAS OF RESEARCH

PRIORITY 1

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

PRIORITY 2

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

PRIORITY 3

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

LOOKING FORWARD - THIS YEAR WE WILL:

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

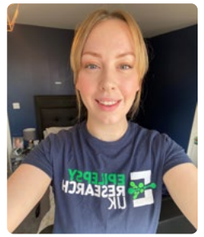






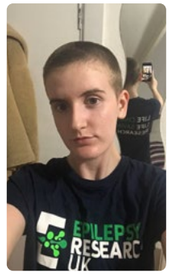


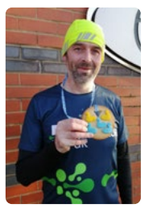
The Slight
NORTH RUN



25 KM
FOR
EPILEPSY








TRUSTEES' REPORT AND FINANCIAL STATEMENTS

YEAR ENDING 31ST MARCH 2021

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

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

Reference and administrative details

Directors and Trustees

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

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

President

Professor Helen Cross MB ChB PhD FRCP(UK) FRCPCH

Chief Executive

Ms Maxine Smeaton MSc PGDip MInstF

Independent auditors

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

Bankers

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

Solicitors and Company Secretary

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

Registered and Head Office

Charity number 1100394
Company number 4873718
CAN Mezzanine, 7-14 Great Dover Street
London SE1 4YR

Objectives and activities for the public benefit

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

The objects of the charity are:

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

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

Key impacts of the global pandemic 2020/21

Income

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

Research

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

- The International Expert Workshop 'Emerging Approaches in the Treatment of Epilepsy' scheduled for March 2021 was postponed.
- We supported costed and no-cost extensions to researchers who were unable to continue their work in the laboratory or on clinical trials due to lockdown
- We extended the deadline for our doctoral training centre programme which is designed to support institutions to create 'PhD hubs' to attract young researchers to the field of epilepsy and facilitate further research and investment. Match funding was required by the host university.
- We took the decision not to fund the Explore Pilot and Endeavour Project studies and to only fund ERUK Emerging Leader Fellowship Awards in the grant round in 2020/21 . We prioritised investment in to building capacity by supporting early-career scientists to develop into epilepsy research leaders with a view to reducing the risk of losing promising epilepsy focused research and researchers.

#ALifeInterrupted Campaign

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

Volunteers

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

Going Concern

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

Plans for future periods

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

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

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

Research grants in 2021

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

Summary of research grants awarded

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

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

Research value and impact

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

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

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

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

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

Fundraising performance in 2020/21

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

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

Our fundraising approach

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

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

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

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

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

General Data Protection Regulation (GDPR)

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

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

Financial review

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

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

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

Specific investment powers of the trustees

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

Structure, governance and management

Governing document

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

Appointment of trustees

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

Trustee induction and training

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

Organisation

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

Related parties

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

Pay policy for senior staff

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

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

Discussions with other parties

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

Risk management and disclosure

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

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

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

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

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

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

Reserves policy

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

Statement of trustees' responsibilities

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

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

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

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

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

Statement as to disclosure of information to auditors

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

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

By order of the Board of Trustees

Professor Matthew Walker
Chair, Board of Trustees

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

We have audited the financial statements of Epilepsy Research UK (the Charity) for the year ended 31st March 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the Charity's trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the Charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Opinion on financial statements

In our opinion the financial statements:

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

Basis of opinion

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

Conclusions relating to going concern

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

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

Other information

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

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

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

We have nothing to report in respect of the following matters in relation to which the Charities Act 2011 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us;
- the financial statements are not in agreement with the accounting records and returns;
- we have not received all the information and explanations we require for our audit;
- the directors were not entitled to take advantage of the small companies exemption from the requirement to prepare a strategic report.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, set out on page 36, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view. And for such internal control as they determine is necessary to enable the preparation of the financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the Charity or to cease operation, or have no realistic option but to do so.

Our responsibilities for the audit of the financial statements

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

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

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

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

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

Statement of Financial Activities (including the Income & Expenditure Account)

for the year ended 31st March 2021

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

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

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

Balance Sheet at 31st March 2021

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

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

Prof Matthew Walker
Chair

Judith Spencer-Gregson FCA
Treasurer

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

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

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

Notes
forming part of the financial statements

1 Accounting policies

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

a) Basis of preparation

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

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

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

b) Fixed assets

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

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

c) Incoming resources

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

d) Resources expended

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

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

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

e) Donated services

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

f) Interest receivable

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

g) Grants committed

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

h) Pension costs

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

i) Value Added Tax (VAT)

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

j) Operating leases

The charity has no current operating leases.

k) Funds

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

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

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

l) Taxation

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

2 Donations and Legacies

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

Donations and Legacies 2020

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

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

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

3 Other Trading Activities

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

4 Investment Income

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

5 Costs of generating funds

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

6 Research Grants Committed

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

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

7 Other Research Activities

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

Other Research Activities 2020

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

8 Support and Governance costs

	Support Costs £	Governance Costs £	Total 2021 £	Total 2020 £
Staff costs	-	9,333	9,333	8,313
Other staff costs	13,400	-	13,400	-
Office rent & facilities	31,758	-	31,758	32,780
Office running costs	20,072	-	20,072	31,389
IT & bank charges	16,265	-	16,265	28,983
Investment fees	-	18,924	18,924	10,118
Audit	-	4,600	4,600	4,620
Trustee meetings & expenses	-	-	-	2,327
Legal & professional fees	-	3,325	3,325	8,565
	81,495	36,182	117,677	127,095
Basis of Allocation				
Allocated to fundraising costs	16,884	10,415	27,299	23.20%
Allocated to charitable activities	64,611	25,767	90,378	76.80%
	81,495	36,182	117,677	100%

Support and Governance costs 2020

	Support Costs £	Governance Costs £	Total 2020 £
Staff costs	-	8,313	8,313
Office rent and facilities	32,780	-	32,780
Office running costs	31,389	-	31,389
IT and bank charges	28,983	-	28,983
Investment fees	10,118	-	10,118
Audit	-	4,620	4,620
Trustee meetings & expenses	-	2,327	2,327
Legal & professional fees	-	8,565	8,565
	103,270	23,825	127,095
Basis of Allocation			
Allocated to fundraising costs	22,985	5,468	28,453	22.95%
Allocated to charitable activities	80,285	18,357	98,642	77.05%
	103,270	23,825	127,095	100%

9 Net incoming resources are after charging the following:

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

10 Staff Costs

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

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

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

	2021	2020
Charitable activities	6.01	5.7
Fundraising	1.79	1.8
Governance	0.10	0.1
	7.90	7.6

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

11 Investments

	2021 £	2020 £
Market value 1 April 2020	2,016,232	1,056,210
Acquisitions	469,964	1,000,000
Sales	(472,588)	-
Investment charges	(18,924)	(9,617)
Income reinvested	63,169	37,587
	2,057,853	2,084,180
Net gain/(loss) realised	664	-
Net gain/(loss) unrealised	253,089	(67,948)
Market value 31 March 2021	2,311,606	2,016,232
Analysis of investments		
Quoted Charity Common Investment funds	2,294,209	1,306,439
Medium and long term	17,397	709,793
Cash on deposit	2,311,606	2,016,232

12 Debtors

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

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

13 Cash Movements

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

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

Cash Movements 2020

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

14 Liabilities

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

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

15 Unrestricted Funds

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

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

Unrestricted Funds 2020

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

16 Restricted Funds

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

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

Restricted Funds 2020

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

17 Analysis of Net Assets between Funds

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

Analysis of Net Assets between Funds 2020

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

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 Commitee (SAC). Trustees and SAC members are eligible to submit funding applications to Epilepsy Research UK, but they must declare any conflicts of interest concerning grant applications and are excluded from any discussion regarding the merits of such applications. Grants awarded in March 2021 included £250,000 to University of Newcastle where Dr Rhys Thomas has an interest and £250,000 to University of Edinburgh where Professor Mike Cousin has an interest. Both awards were to establish a PhD hub and not a direct grant to the Trustee.

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

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

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

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

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

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