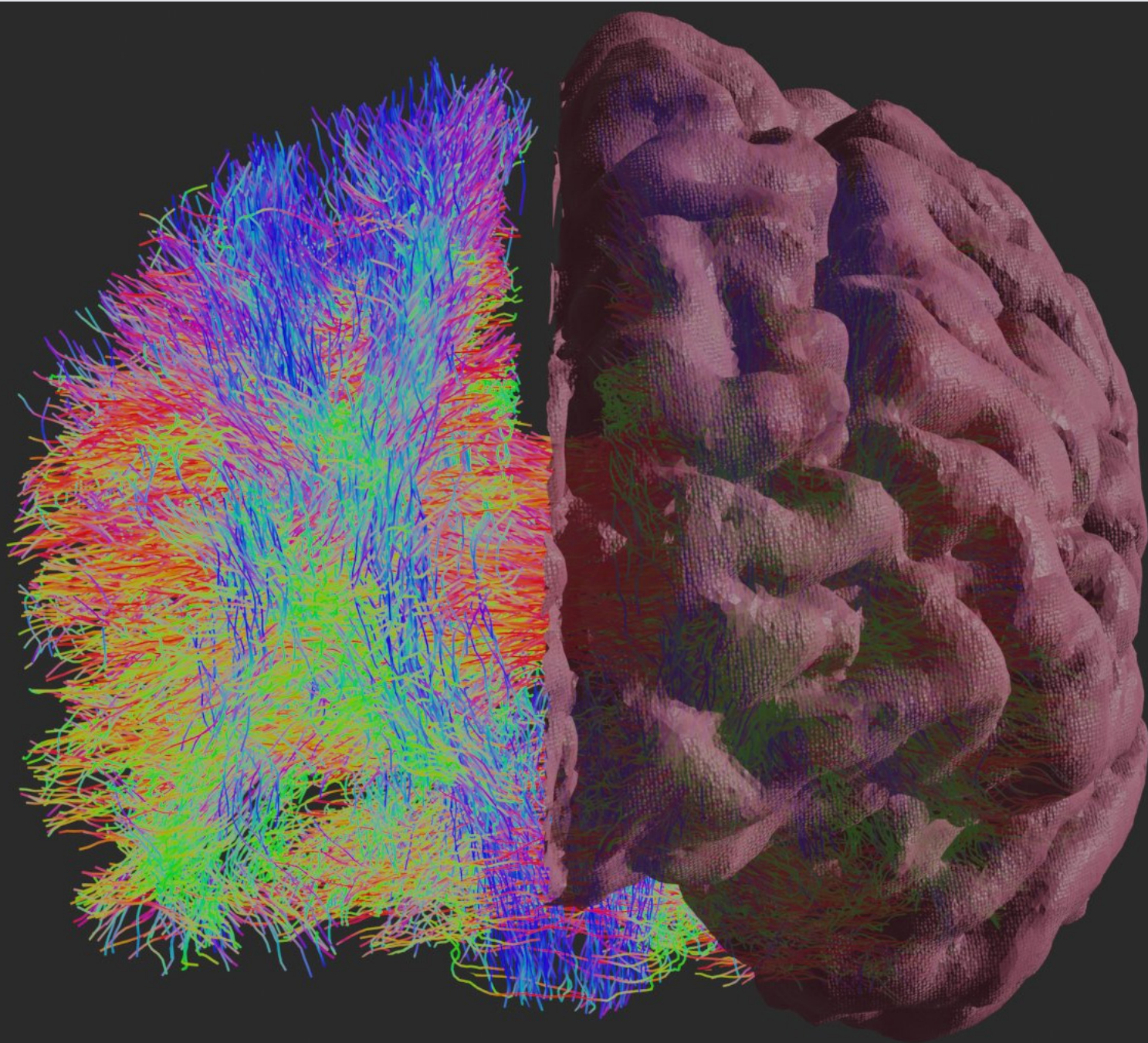


RADICALLY ADVANCING RESEARCH INTO EPILEPSY

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

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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

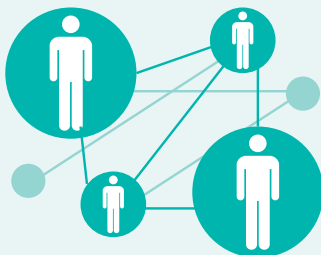


The official launch of the Epilepsy Research Institute at a reception at

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



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.

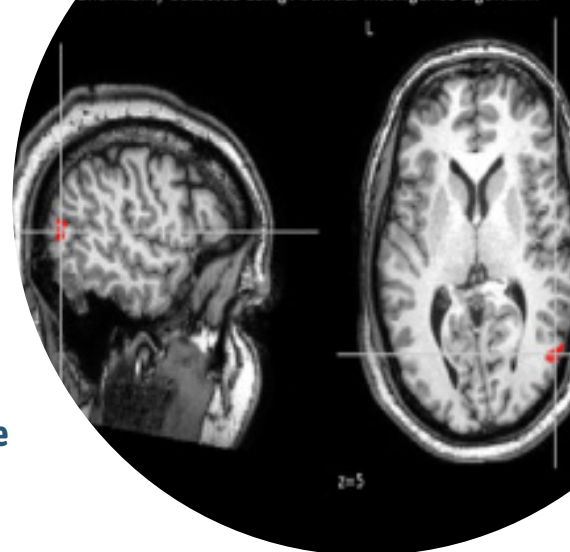
Alongside funding ground-breaking studies, we are also committed to strengthening the epilepsy research ecosystem by driving strategic investment and developing partnerships and collaborations between academia, the NHS, industry, funders, patient groups and people affected by epilepsy.

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



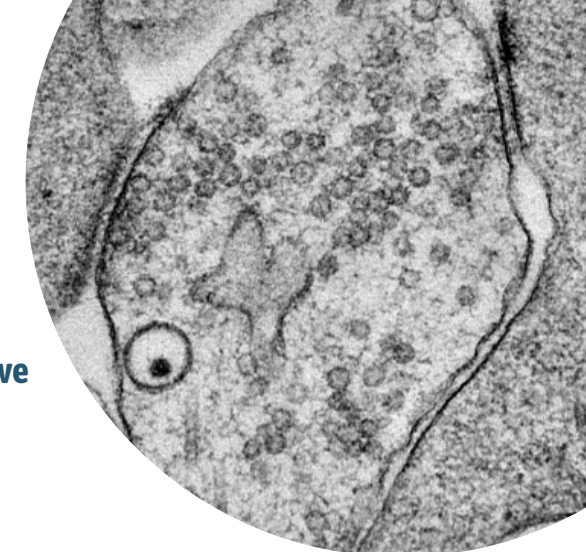
Fundamental Science Co-Lead
Professor Juan Burrone
King's College London



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.

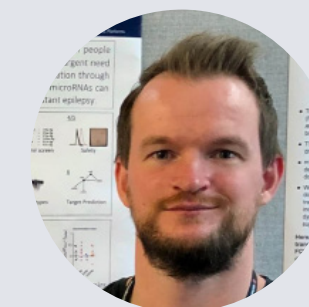
Advanced Therapeutics & Disease Modification Theme Leads



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.

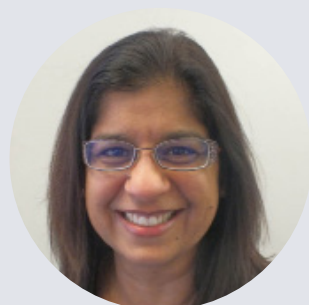
Research ambitions

- 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



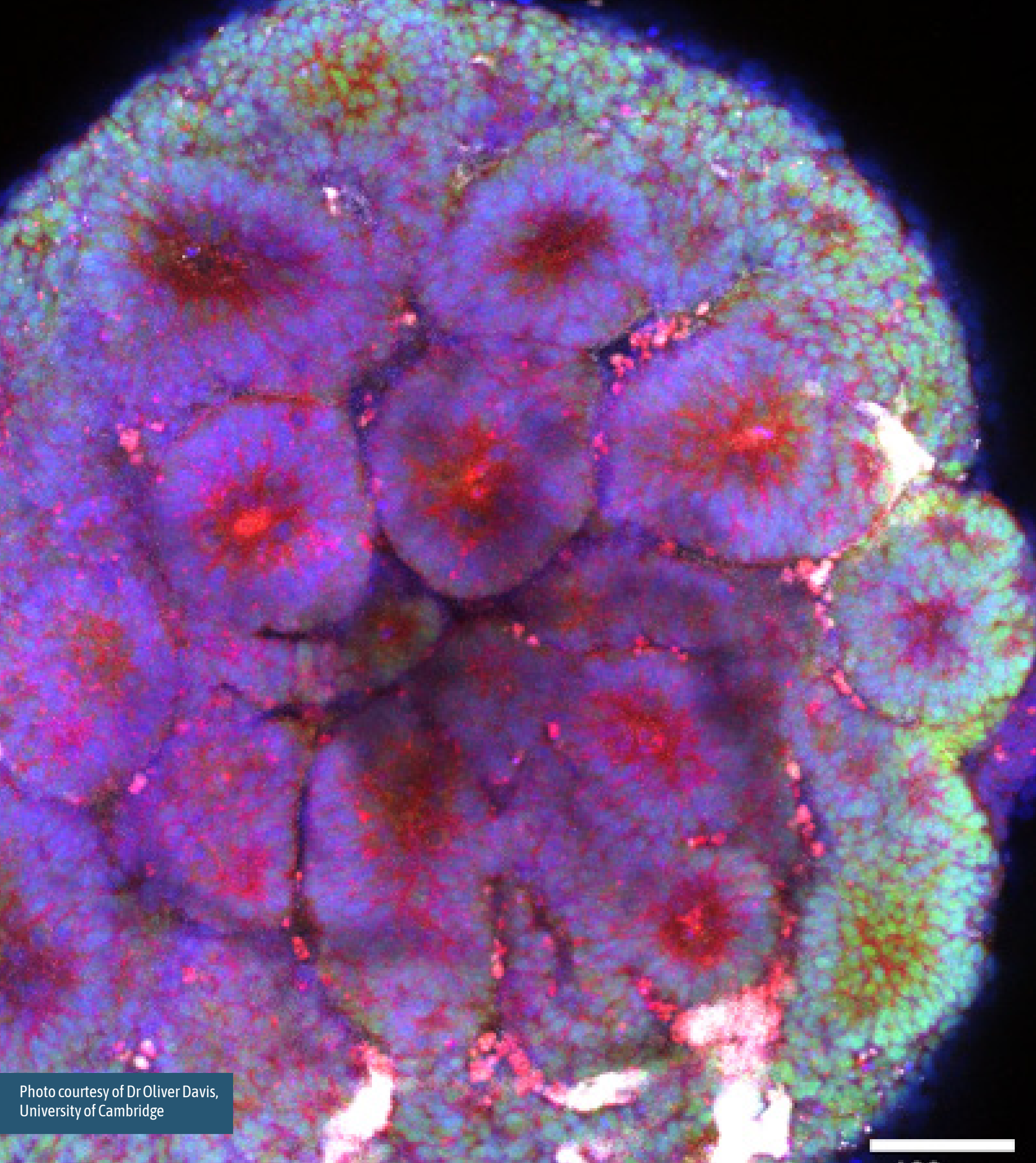
Data Co-Lead
Professor John Terry
University of Birmingham



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.



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

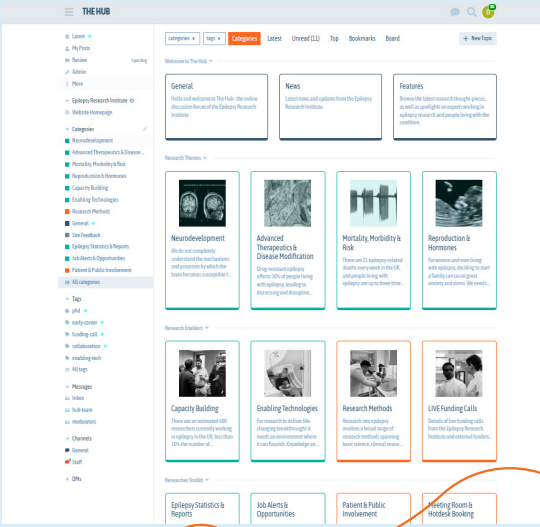
At the end of March 2024, the Institute launched a survey to assess the current capacity in epilepsy research. Carried out as part of the Institute’s Capacity Building strategic theme, the survey will help us gain a better understanding of the research ecosystem, including the facilitators and barriers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

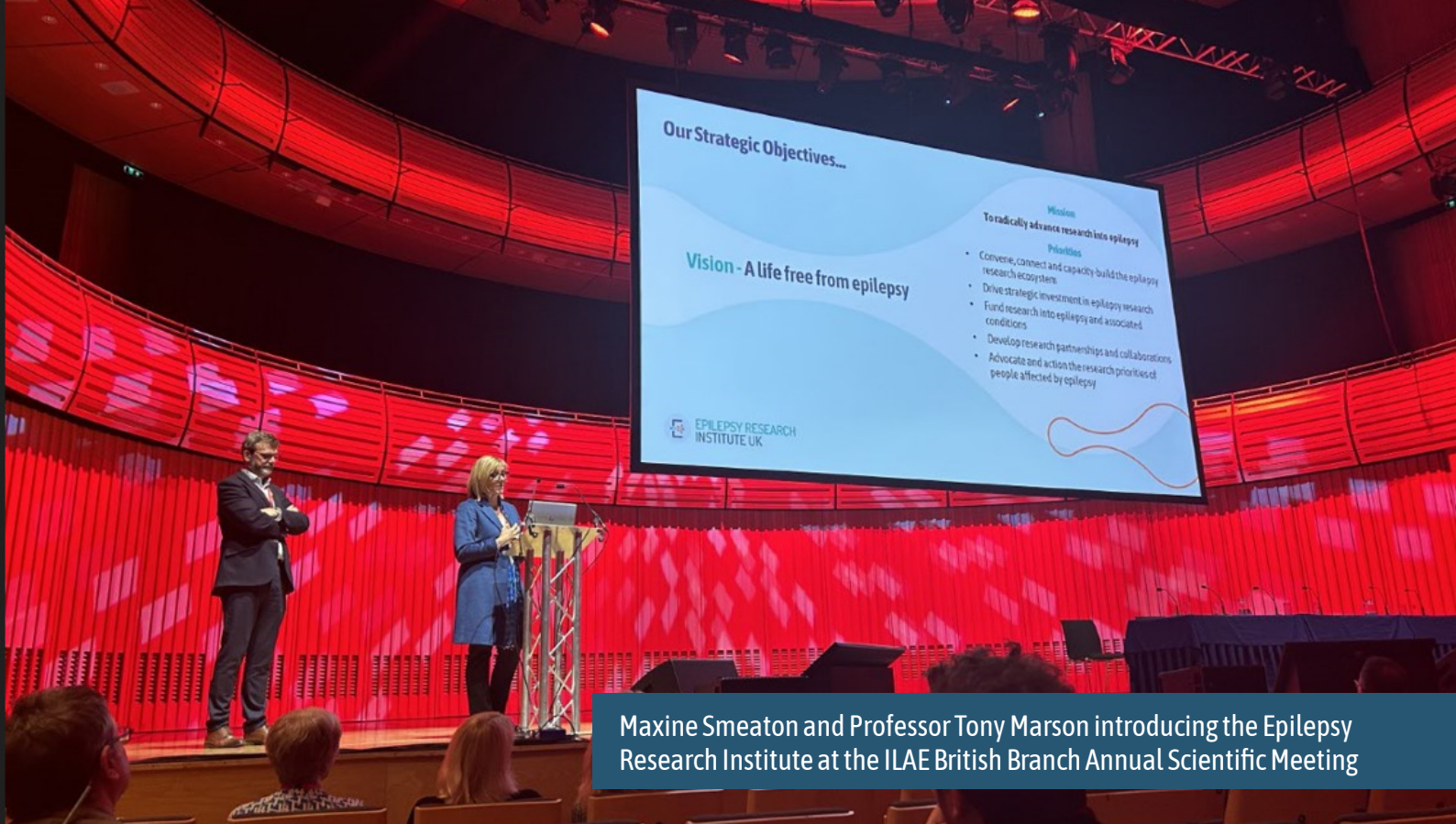
Results from this survey will help inform the Capacity Building theme’s work by clarifying the current capacity and ensuring we measure our success from the correct baseline.

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.

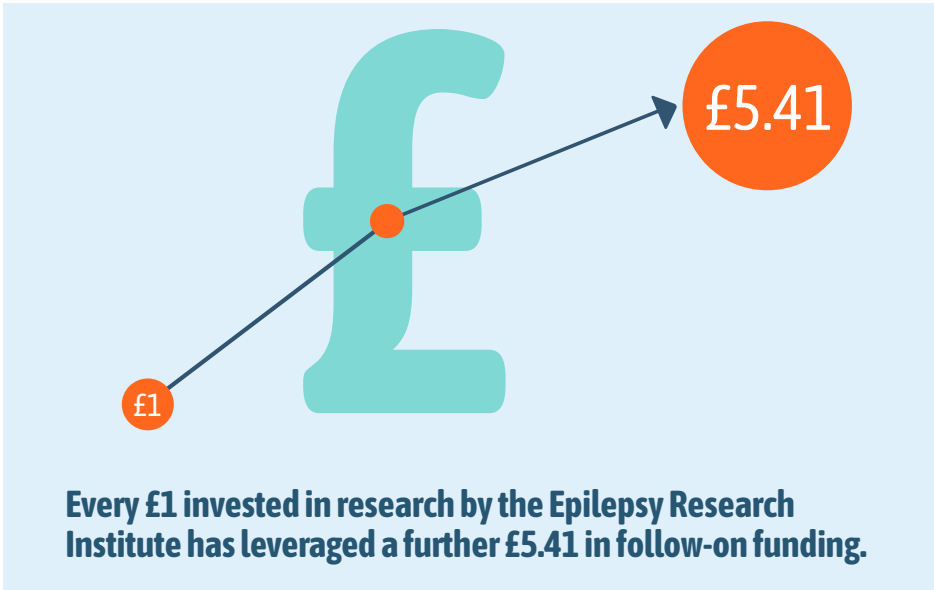
At the conference, the Institute ran the regular Neurobiology of Epilepsy session, during which shortlisted early career researchers competed for the Celine Newman Neurobiology of Epilepsy Award. Dr Laura Smith from Newcastle University was the winner of this year’s award. Dr Smith is a postdoctoral 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.



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

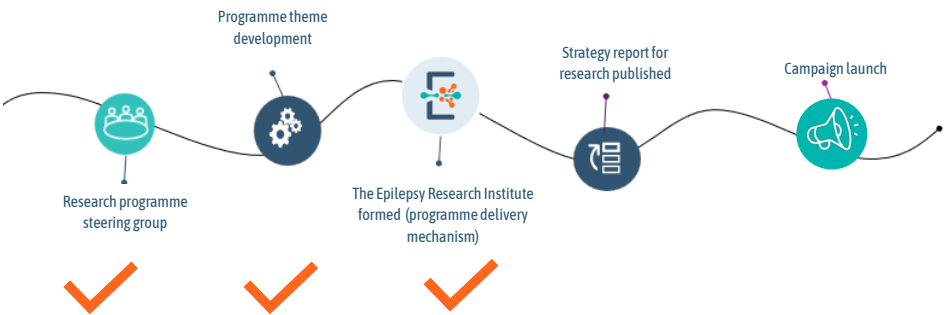
As part of the formation and announcement of the Epilepsy Research Institute, we have hosted large events in venues such as 10 Downing Street and The Francis Crick Institute. We were able to showcase our work and ambitions to the many potential funders and partners who were present at these receptions, 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



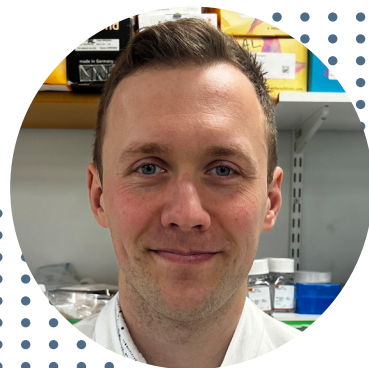
Development of a breath test for the diagnosis of epilepsy and the prediction of seizures

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

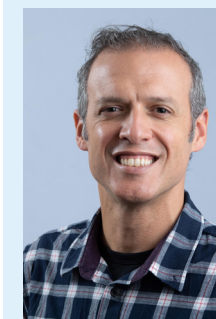
WHAT WE DID TO ADVOCATE & ACTION RESEARCH PRIORITIES OF PEOPLE AFFECTED BY EPILEPSY

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 therapeutic 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 Bernard 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.

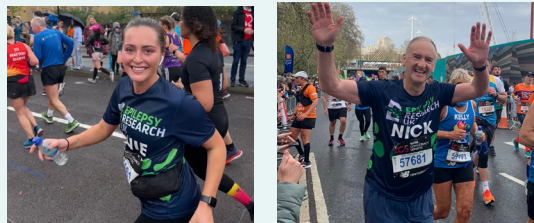
To everyone who bakes, runs, swims, volunteers, donates or has left a gift in their will – your efforts are felt in hospitals, labs and universities across the UK. The record-breaking research funding and the establishment of the Epilepsy Research Institute has only been possible because of your achievements. 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	Previously (until 20 September 2023):
35 Red Lion Square	7-14 Great Dover Street
London WC1R 4SG	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 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 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		<u>2,046,108</u>	<u>1,549,001</u>	<u>3,595,109</u>	<u>3,605,370</u>
Expenditure on:					
Cost of raising funds					
Raising Funds	6	<u>177,658</u>	<u>-</u>	<u>177,658</u>	<u>173,303</u>
Charitable activities					
Research grants committed	7	1,999,070	-	1,999,070	1,705,986
Other research activities	8	<u>870,782</u>	<u>43,753</u>	<u>914,535</u>	<u>779,137</u>
Total charitable expenditure		<u>2,869,852</u>	<u>43,753</u>	<u>2,913,605</u>	<u>2,485,123</u>
Total expenditure		<u>3,047,510</u>	<u>43,753</u>	<u>3,091,263</u>	<u>2,658,426</u>
Net unrealised gains / (losses) on investments		<u>278,842</u>	<u>-</u>	<u>278,842</u>	<u>(263,090)</u>
Net income/(expenditure) for the year		<u>(722,560)</u>	<u>1,505,248</u>	<u>782,688</u>	<u>683,854</u>
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		<u>3,394,171</u>	<u>1,413</u>	<u>3,395,584</u>	<u>2,711,730</u>
Total funds carried forward at 31 March	17	<u>4,178,272</u>	<u>-</u>	<u>4,178,272</u>	<u>3,395,584</u>

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	<u>7,552,532</u>	3,740,842
		7,552,532	3,740,842
Current assets			
Debtors	13	846,091	1,868,069
Cash at bank and in hand		<u>2,197,361</u>	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		<u>(373,706)</u>	2,498,582
Total assets less current liabilities		7,178,826	6,239,424
Creditors: amounts falling due within one year	14	<u>(3,000,554)</u>	(2,843,840)
Total net assets		<u>4,178,272</u>	<u>3,395,584</u>
The funds of the charity			
Unrestricted funds	15		
Designated funds		3,278,272	2,494,171
General fund		<u>900,000</u>	900,000
		4,178,272	3,394,171
Restricted funds	16	<u>-</u>	1,413
Total charity funds		<u>4,178,272</u>	<u>3,395,584</u>

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	<u>1,946,632</u>	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	<u>226,493</u>	168,269
Net cash inflow/(outflow) from investing activities	<u>(3,306,352)</u>	61,505
Increase/(decrease) in cash and cash equivalents in the year	<u>(1,359,720)</u>	531,046
Cash and cash equivalents at the beginning of the year	<u>3,557,081</u>	3,026,035
Cash and cash equivalents at the end of the year	<u><u>2,197,361</u></u>	<u><u>3,557,081</u></u>
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	<u>156,714</u>	(100,676)
Net cash from/used in operating activities	<u><u>1,946,632</u></u>	<u><u>469,541</u></u>
Analysis of cash and cash equivalents		
Cash deposits	1,886,696	2,852,508
Cash at bank	<u>310,665</u>	704,573
Net Cash from/used in operating activities	<u><u>2,197,361</u></u>	<u><u>3,577,081</u></u>

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.

	As at 31 Mar 23	Cashflows	As at 31 Mar 24
Cash deposits and cash at bank	<u><u>3,557,081</u></u>	<u><u>(1,359,720)</u></u>	<u><u>2,197,361</u></u>

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
	<u>1,816,004</u>	<u>70,150</u>	<u>1,886,154</u>	<u>1,967,065</u>

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
	<u>1,666,313</u>	<u>300,752</u>	<u>1,967,065</u>

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
	<u>-</u>	<u>-</u>	<u>-</u>	<u>1,451,840</u>

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
	<u>3,608</u>	<u>-</u>	<u>3,608</u>	<u>18,193</u>

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
	<u>226,496</u>	<u>-</u>	<u>226,496</u>	<u>168,269</u>

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
	<u>177,658</u>	<u>-</u>	<u>177,658</u>	<u>173,303</u>

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	<u>6,314,802</u>	<u>5,609,511</u>

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
	<u>870,782</u>	<u>43,753</u>	<u>914,535</u>	<u>779,137</u>

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
	<u>705,613</u>	<u>73,524</u>	<u>779,137</u>

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
	<u>154,986</u>	<u>95,147</u>	<u>250,133</u>	<u>212,768</u>

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%
	<u>154,986</u>	<u>95,147</u>	<u>250,133</u>	<u>100.00%</u>

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
	<u>108,736</u>	<u>104,032</u>	<u>212,768</u>

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
	<u>100.00%</u>	<u>108,736</u>	<u>104,032</u>	<u>212,768</u>

10 TOTAL AUDITOR'S REMUNERATION

	2024 £	2023 £
Remuneration in relation to the audit of the financial 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
	<u>601,685</u>	<u>489,136</u>

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
	<u>10.00</u>	<u>10.05</u>

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 £6,311 for 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
	<u>3,430,619</u>	<u>3,843,068</u>	<u>7,273,687</u>	<u>4,003,929</u>
Net gain/(loss) realised	3	0	3	3
Net gain/(loss) unrealised	0	278,842	278,842	(263,090)
Market value 31 March 2024	<u>3,430,622</u>	<u>4,121,910</u>	<u>7,552,532</u>	<u>3,740,842</u>

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
	<u>7,552,532</u>	<u>3,740,842</u>

During the year the Trustees transferred additional cash from bank accounts to a liquidity 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
	<u>846,091</u>	<u>1,868,069</u>

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

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
	<u>6,417,712</u>	<u>5,770,408</u>

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			Total
	Research Fund 2024 £	#Every1Ending Epilepsy 2024 £	General Fund 2024 £	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	<u>3,084,303</u>	<u>193,969</u>	<u>900,000</u>	<u>4,178,272</u>

Unrestricted Funds 2023

	Designated Funds			Total
	Research Fund 2023 £	#Every1Ending Epilepsy 2023 £	General Fund 2023 £	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	<u>2,213,953</u>	<u>280,218</u>	<u>900,000</u>	<u>3,394,171</u>

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	-
	<u>73,242</u>	<u>1,549,001</u>	<u>(43,754)</u>	<u>(1,506,660)</u>	<u>-</u>

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
	<u>73,242</u>	<u>1,752,592</u>	<u>(1,824,421)</u>	<u>1,413</u>

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)
	<u>4,178,272</u>	<u>-</u>	<u>4,178,272</u>

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)
	<u>3,394,171</u>	<u>1,413</u>	<u>3,395,584</u>

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

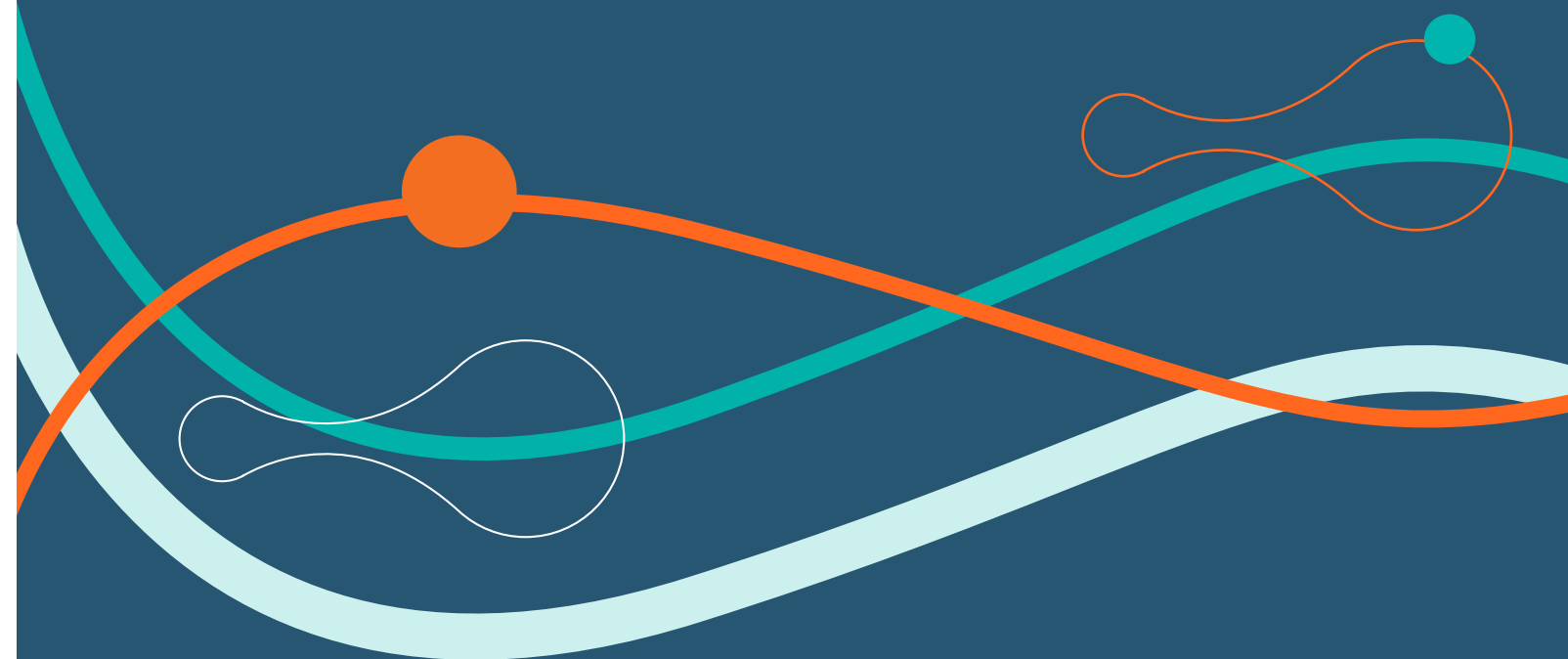
20 STATEMENT OF FINANCIAL ACTIVITY FOR THE YEAR ENDED 31 MARCH 2023 (PRIOR YEAR)

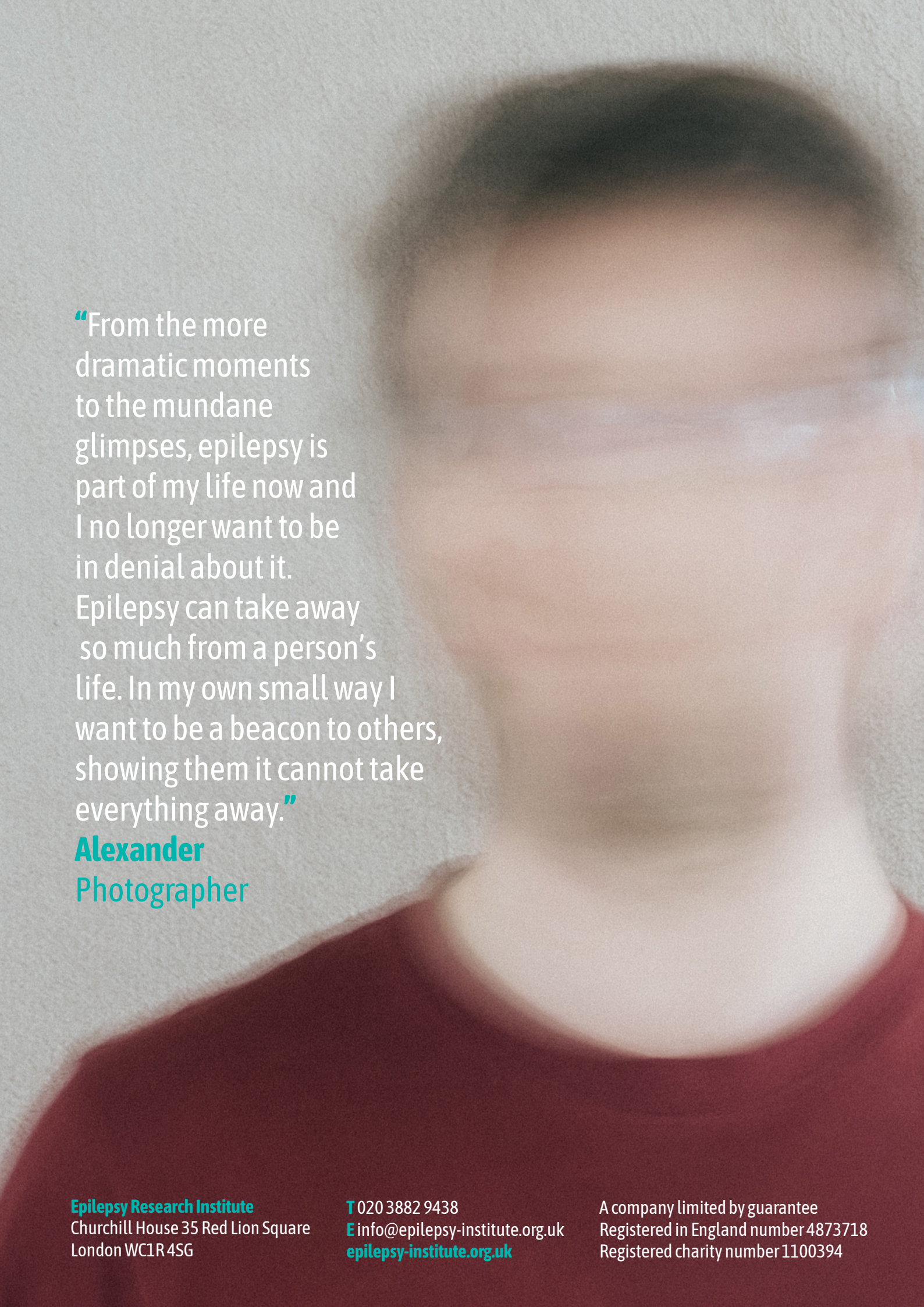
(Including the Income & Expenditure Account)

	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