

STRENGTHENING THE EPILEPSY RESEARCH ECOSYSTEM

Annual Report 2024-2025



EPILEPSY RESEARCH
INSTITUTE UK

epilepsy-institute.org.uk

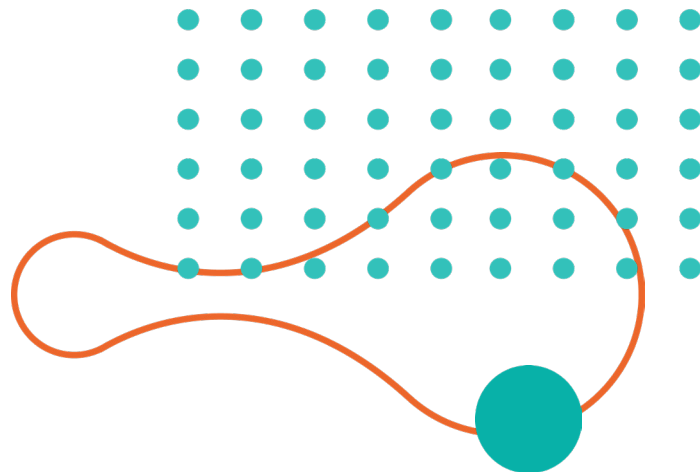


“For me, hope came in the form of research. At the age of 15, I took part in a groundbreaking project by Dr Antonio Valentin, which changed my life. Thanks to this research, I have since been seizure-free for 10 years.”-

Sophie, Epilepsy Research Institute Supporter



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OUR YEAR IN NUMBERS



FUNDING

**£1.71
million**

Invested in our
2025 Research Awards



327

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



MEMBERS

770

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



Over 690

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

**SHAPE
NETWORK**

PARLIAMENTARY WORK



405

**MPs contacted about
epilepsy research**

5

**written parliamentary
questions tabled**

19 MPs

**signed up as One
in 100 campaign
champions**

RESEARCH



**The Epilepsy Research Institute is
supporting**

40

active research projects across

18

institutions, involving over

100

**researchers and collaborators in
the UK and internationally**



WELCOME FROM OUR CHAIR AND CHIEF EXECUTIVE



Professor Matthew Walker
Chair of Trustees



Rosemarie Pardington
Chief Executive

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

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

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

targeted fundraising, funding partnerships and strategic leveraging.

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

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

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

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

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

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

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

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

Raising awareness of epilepsy is one of our three strategic goals. Without it, we cannot increase research investment from government and other funders. This is why we **launched our One in 100 Campaign** in October last year to highlight the costs to society and shocking

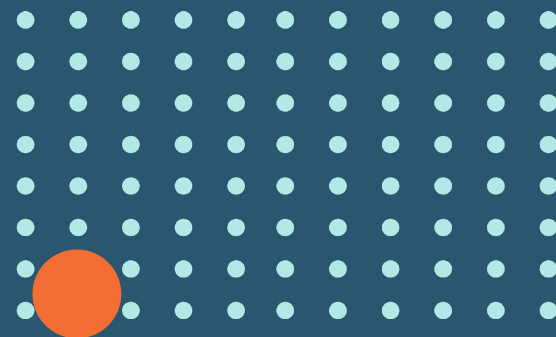
statistics, including, tragically, that there are three epilepsy-related deaths every day in the UK alone. As a result of our campaign, over 400 people have now written to their MPs. So far, 19 MPs have signed up as campaign champions and we have had five written parliamentary questions tabled on epilepsy research. Our One in 100 appeal is helping us begin to raise the essential funds needed to advance epilepsy research.



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

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

OUR INAUGURAL CONFERENCE



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

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

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



Day 1

Highlights of the day included:

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



Day 2

Highlights of the day included:

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

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



Thank you to our sponsors

The Epilepsy Research Institute would like to thank our generous sponsors:

ILAE British Branch, UNEEG Medical, UCB, Epilepsy Action, Neuronostics, Matthew's Friends and Cardonet, for their generous support which enabled this impactful conference to take place.



cardonet



Inspired by patients.
Driven by science.

UNEEG
medical



EPILEPSY
ACTION

OUR VISION, MISSION AND VALUES

Our Vision

A life free from epilepsy

Our Mission

To radically advance research into epilepsy

Our Values

INTEGRITY

We are open and transparent about all aspects of our work and employ the utmost candour in our focus to *'radically advance research into epilepsy'*.

COLLABORATIVE

We appreciate that it is only by working together we will achieve our vision of *'a life free from epilepsy'*. Our teamwork and partnerships reflect our integrity, professional approach and trustworthiness.

HONESTY

We expect a high standard of excellence, supporting the best science with our systematic and rigorous approach to all of our work.

INNOVATIVE

We are courageous and ambitious to enable ground-breaking research and welcome innovative and creative ideas.

DIVERSITY & INCLUSION

We are respectful of all the people working with, and for us, including people living with epilepsy, researchers, collaborators and our supporters, fostering teams across diverse cultures and backgrounds and valuing their views and input.

Our Founding Partners



THE EPILEPSY LANDSCAPE AND GLOBAL PERSPECTIVE

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

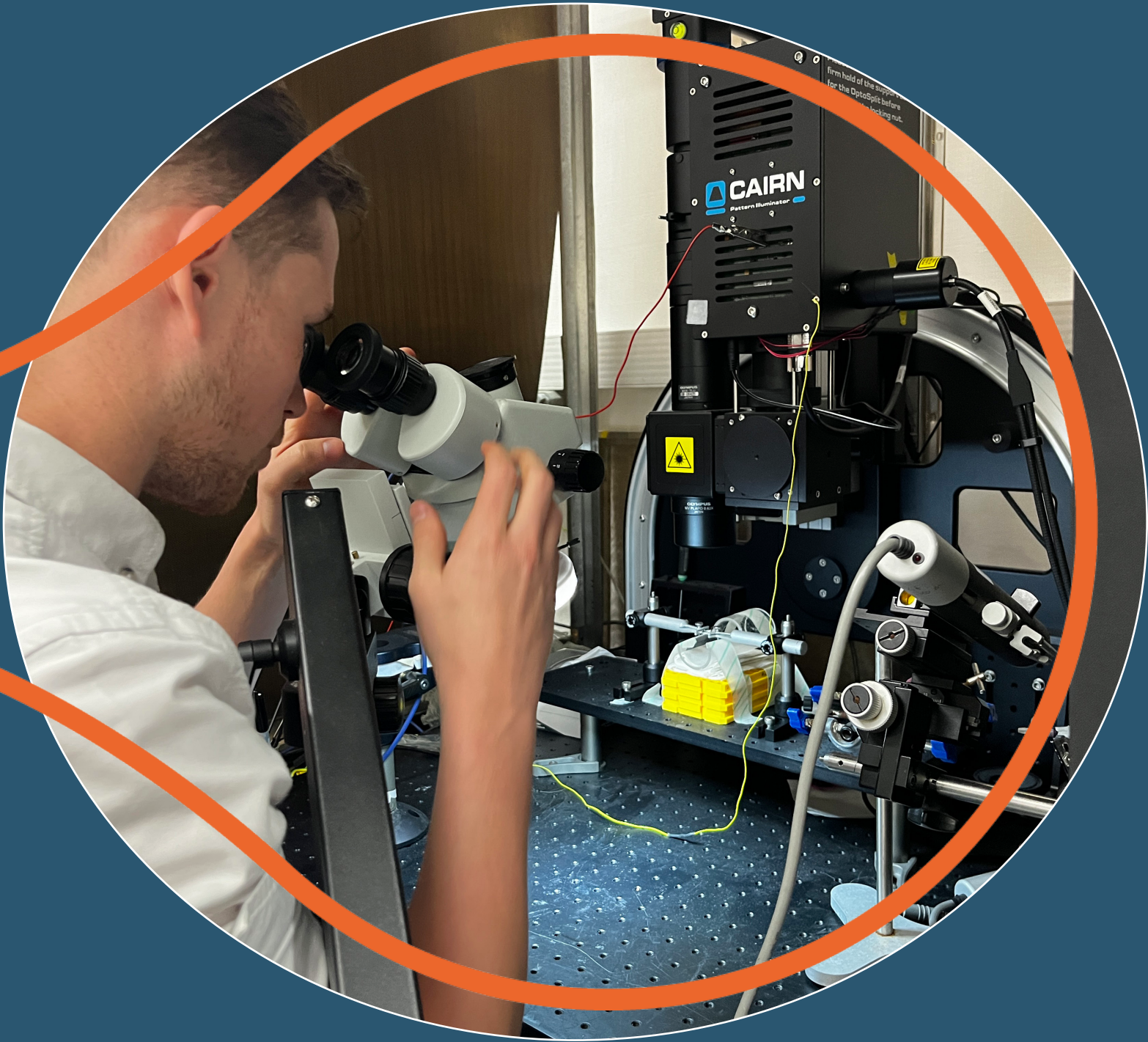
Every year the condition drives 100,000 UK hospital visits and accounts for 1% of all NHS costs, yet stark health inequalities continue to prevent many from accessing timely support. As the Government sets about reforming the NHS, this cost is something that must be urgently addressed.

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

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

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

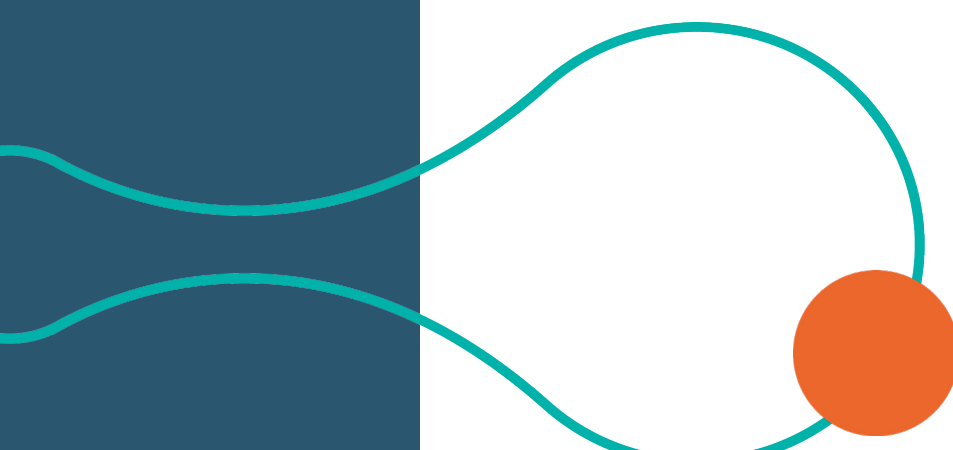
OUR RESEARCH PROGRAMME



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

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

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



BUILDING AND STRENGTHENING THE EPILEPSY RESEARCH COMMUNITY



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

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

Fellowships for future epilepsy research leaders

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

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

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

Enthusing and empowering researchers

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

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

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

“It really inspired me to explore new questions that might be included in my future research plans.”

Navigator Symposium attendee

Strengthening networks

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

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

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

- PhD student

Support from the start

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



CONVENING AND CONNECTING THE RESEARCH COMMUNITY



Epilepsy Research Institute task force groups

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

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

Delivering focused theme workshops

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

Mortality, Morbidity & Risk theme

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

Reproduction & Hormones theme

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

Neurodevelopment theme

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

Advanced Therapeutics & Disease Modification theme

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



Workshop: advancing SUDEP research

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

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

Several recommendations were made, including:

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

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

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

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

OUR PARTNERSHIPS



Strategic partnerships and collaborations

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

Partnering with industry to unlock progress

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

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

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

Broadening our engagement with industry

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



Advancing the agenda for SUDEP research

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

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

Collaboration in Late-Onset and Vascular Epilepsy Research – CLOVER

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

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



UK Dementia Research Institute



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

Joint working with our founding partners

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

Joint Roundtable Event with Epilepsy Scotland



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

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

OUR RESEARCH AWARDS



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

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

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



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

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

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

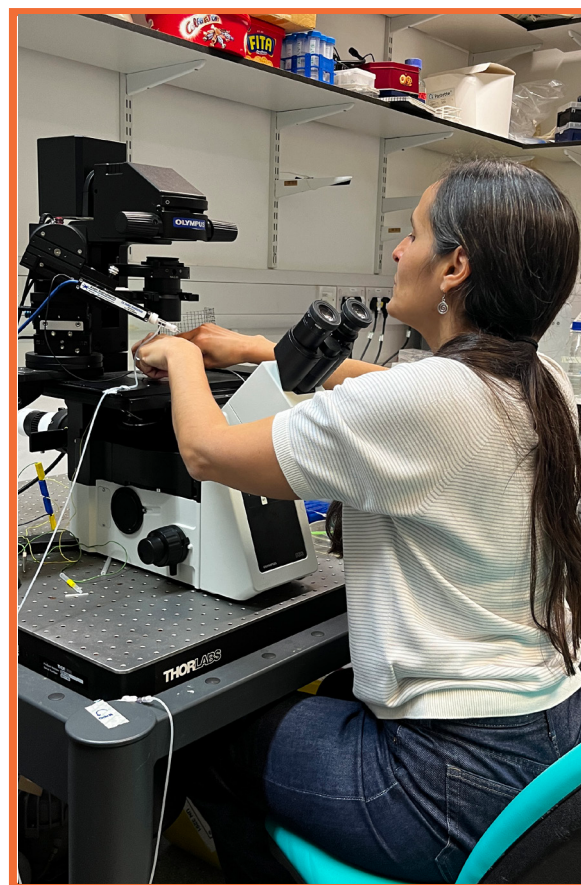
Left: Entry Fellowship winner,
Dr Francesca Chaloner

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

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

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

Right: Emerging Fellowship winner, Marisol Sampedro Castañeda



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

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

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

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



RESEARCH AWARDS 2025



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

GRANT TYPE: Entry Fellowship

GRANT AMOUNT: £97,024

LEAD INVESTIGATOR: Dr Francesca Chaloner

CO-INVESTIGATORS: Dr Samuel Barnes, Professor Michael Johnson

INSTITUTION: Imperial College London

BACKGROUND

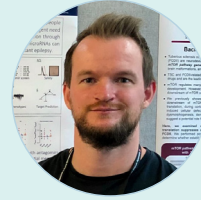
Epilepsy is 2-3 times more common in people with Alzheimer's disease (AD) than in the general population and can make cognition worse. Few studies have investigated the link between these two diseases and the mechanisms underlying this link is unknown.

THE STUDY

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

SIGNIFICANCE

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



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

GRANT TYPE: Endeavour Project Grant

GRANT AMOUNT: £173,770.42

LEAD INVESTIGATOR: Dr Gareth Morris

CO-INVESTIGATOR: Professor Susan Kimber

INSTITUTION: University of Manchester

BACKGROUND

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

THE STUDY

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

SIGNIFICANCE

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



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

GRANT TYPE: Endeavour Project Grant

GRANT AMOUNT: £148,434.03

LEAD INVESTIGATOR: Dr Craig Heath

CO-INVESTIGATORS: Professor Colin McCowan, Dr Rebecca Bromley, Dr John Craig, Dr Alex Marshall

INSTITUTION: NHS Greater Glasgow and Clyde

BACKGROUND

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

THE STUDY

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

SIGNIFICANCE

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



What cellular processes help to stop seizures?

GRANT TYPE: Endeavour Project Grant

GRANT AMOUNT: £174,700

LEAD INVESTIGATOR: Professor Andrew Trevelyan

INSTITUTION: Newcastle University

BACKGROUND

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

THE STUDY

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

SIGNIFICANCE

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

RESEARCH AWARDS 2025



Finding the silent causes of seizure risk

GRANT TYPE: Emerging Leader Fellowship

GRANT AMOUNT: £300,000

LEAD INVESTIGATOR: Dr Robert Graham

CO-INVESTIGATOR: Professor Dimitri Kullmann

INSTITUTION: UCL Queen Square Institute of Neurology

BACKGROUND

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

THE STUDY

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

SIGNIFICANCE

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



Investigating how calcium channel dysfunction causes epilepsy

GRANT TYPE: Emerging Leader Fellowship

GRANT AMOUNT: £299,998.77

LEAD INVESTIGATOR: Dr Marisol Sampedro Castañeda

CO-INVESTIGATORS: Dr Roope Mannikko, Professor Dimitri Kullmann

INSTITUTION: UCL Queen Square Institute of Neurology

BACKGROUND

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

THE STUDY

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

SIGNIFICANCE

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



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

GRANT TYPE: Endeavour Project Grant

GRANT AMOUNT: £174,981.70

LEAD INVESTIGATOR: Dr Edmond Shu Lim Ho

CO-INVESTIGATORS: Professor Sameer Zuberi, Professor Neil Patel

INSTITUTION: University of Glasgow

BACKGROUND

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

THE STUDY

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

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

SIGNIFICANCE

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



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

GRANT TYPE: Endeavour Project Grant

GRANT AMOUNT: £146,404.75

LEAD INVESTIGATOR: Professor Sameer Zuberi

CO-INVESTIGATORS: Dr Ross Langley, Professor Andreas Brunklaus, Professor Neil Patel

INSTITUTION: Royal Hospital for Children and University of Glasgow

BACKGROUND

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

THE STUDY

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

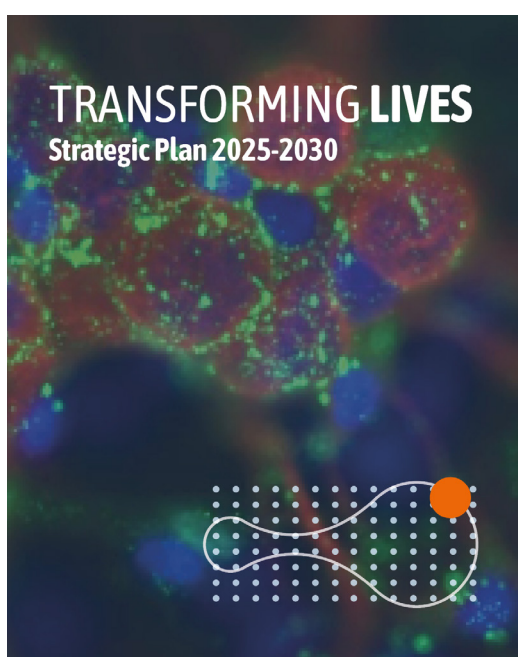
SIGNIFICANCE

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

TWO NEW PUBLICATIONS SET OUT OUR VISION

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

Strategic Plan 2025-2030



 EPILEPSY RESEARCH
INSTITUTE UK

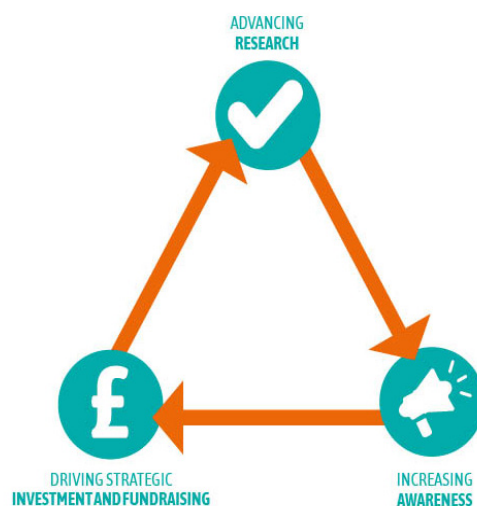
epilepsy-institute.org.uk

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

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

Key Strategic Goals

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



Research Roadmap 2024



epilepsy-institute.org.uk

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

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

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

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

SHAPE NETWORK

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

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

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

Application Clinics

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

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

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

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

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

Epilepsy Research Institute as co-applicants

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

EpiSafe Programme

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

Activity so far

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

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

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

Using AI and data analysis to tackle drug-resistant epilepsy

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

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

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

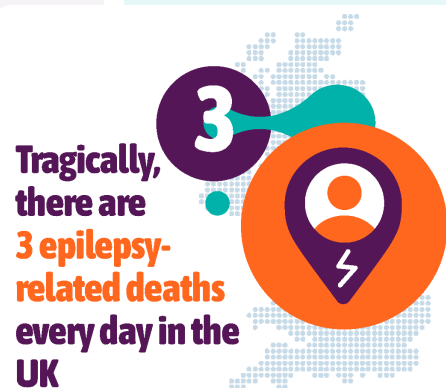
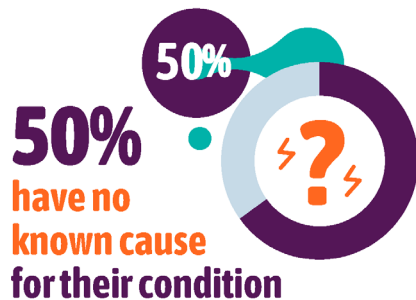
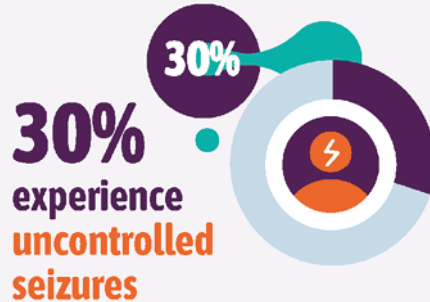
The two centres, King's and Swansea, have previously worked independently to develop state-of-the-art methods to extract relevant information from thousands of health records. Joining forces and working with the SHAPE network will allow them to accelerate progress. We are excited to provide support for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

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

THE **ONE IN 100** CAMPAIGN

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

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



The campaign has three aims:

1

Raising awareness for
the One in 100

2

Accelerating
investment for the
One in 100

3

Radically advancing
research for
the One in 100

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

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

ONE IN 100 Facing fear, finding hope

One in 100 people live with epilepsy and each year:



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



It costs the NHS **£2 billion**

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

£21 for epilepsy

£97 for dementia

£234 for Parkinson's disease

It's time to change these numbers for good.

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

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

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

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

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

One in 100
people live
with epilepsy
in the UK



ONE IN 100 THE PEOPLE BEHIND THE NUMBERS

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



Joy

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

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

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



Sophie

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

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

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



Murray

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

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

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

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



Faye

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

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

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

OUR RESEARCH OUTCOMES



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

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

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

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

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

Grant holders: Matthew Walker (Principal Investigator); **Co-applicants:** Eleonora Lugara, George Hanna, Ilaria Belluomo

Host Institutions: University College London, Imperial College London

Duration of project: 01/12/2021 - 30/11/2024

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

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

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

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

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

Grant holders: Beate Diehl (Principal Investigator), **Co-applicant:** Louis Lemieux

Host Institution: University College London

Duration of project: 03/08/2020 - 30/12/2024

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

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

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

Grant holders: Owen Pickrell (Principal Investigator); **Co-applicants:** Lyons RA; Lacey AS; Vuksanovic V; Akbari A; Powell R; Sawhney IMS; Smith PE; Hamandi K; Anderson J; Johnston A

Host Institution: Swansea University

Duration of project: 01/12/2022 - 30/11/2023

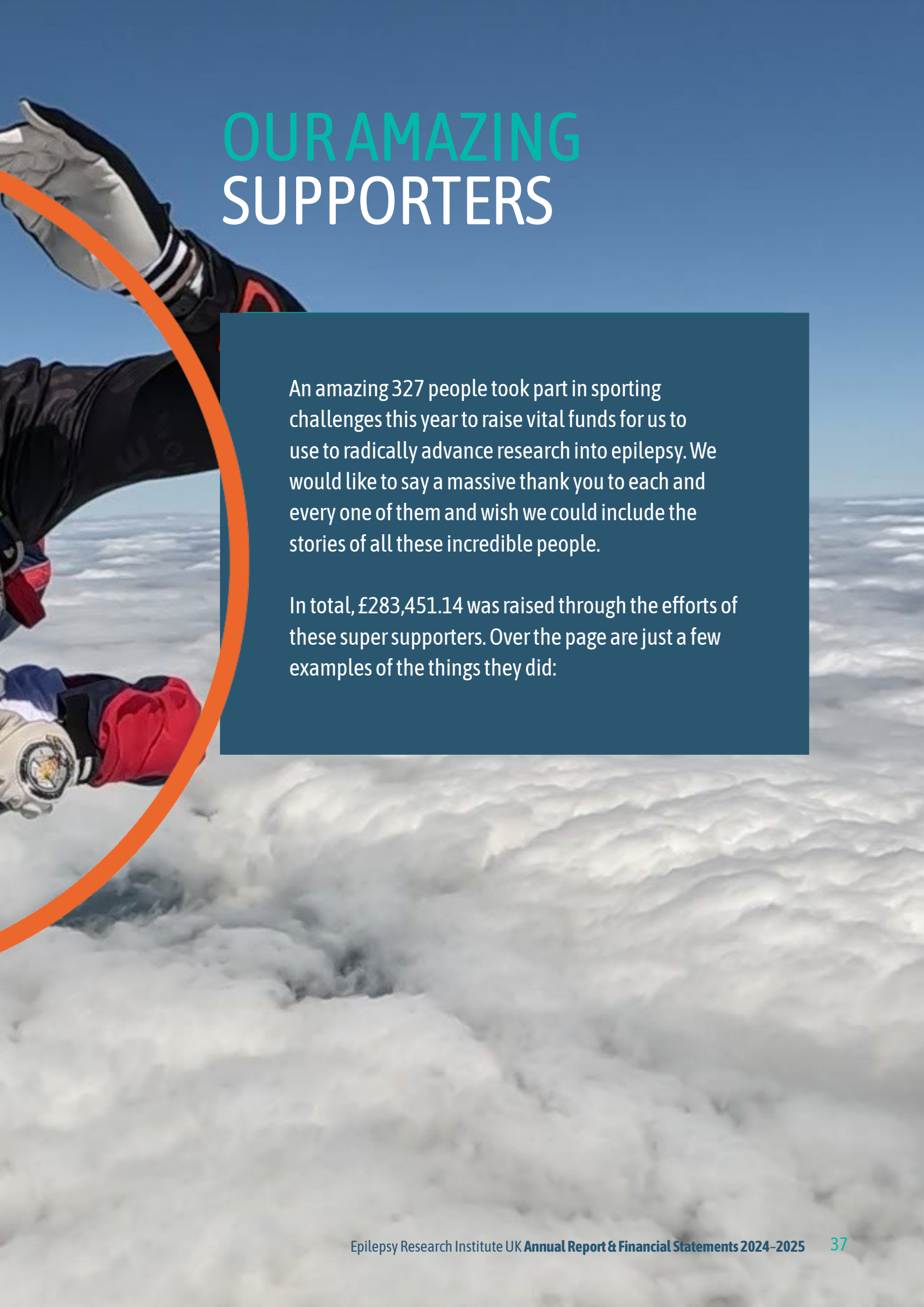
This project developed a computer system called ExECT (Extraction of Epilepsy Clinical Text), which uses natural language processing (NLP) to automatically read clinic letters and extract key information. This information allowed researchers to learn more about refractory epilepsy, where people continue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

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

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

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





OUR AMAZING SUPPORTERS

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

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

SUPPORTER EVENTS

London Marathon

April 2024

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

April 2025

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

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



Left: Lizzie Smith after running the London Marathon 2024

Right: Andrew Rosewell after running the London Marathon 2025



Below: Gracie Cameron with friends and family in Madrid



Above: Gracie after finishing the Madrid Marathon 2025

Madrid Marathon - April 2025

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

Right: Julia Pyke at the Skydive 2025



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

Skydive - May 2025

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

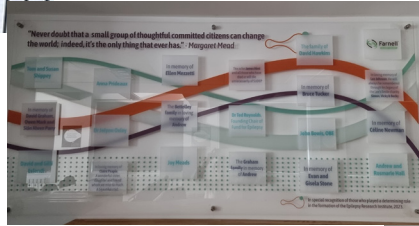
"My son has epilepsy, as do some of our family members and friends, so it's a really really important cause that we want to raise money for." – Julia Pyke



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

Farnell Golf Day 2024

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



Left: The Founders Wall at Epilepsy Research Institute Head Office

Founders' Wall

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

Right: David Bowmaker with his family after the run



Below: Ariel Chelsey after running the Great North Run 2024



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



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

Great North Run - September 2024

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

Below: Martin Verspeak with granddaughter Eliza and family



1,000 Mile Bike Ride

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

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

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

The directors hereafter referred to as the Trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 March 2025.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

REFERENCE AND ADMINISTRATIVE DETAILS

Directors and Trustees

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

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

President

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

Chief Executive

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

Independent auditors

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

Bankers

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

Solicitors

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

Registered Charity number 1100394
Registered Company number 4873718

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

OBJECTIVES AND ACTIVITIES FOR THE PUBLIC BENEFIT

Objectives and activities for the public benefit

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

The objects of the charity are:

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

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

Financial Review

In 2024-25 overall incoming resources were £1,700,383 (2024: £3,595,109) as we did not receive funding from grants as in the previous year (2024: 1,478,851). The costs of raising funds were £269,065 (2024: £177,658) as we strengthened our team in order to achieve the targets set in our new five-year strategy. We were able to maintain a similar level of expenditure

on charitable activities of £2,585,987 (2024: £2,913,605) and plans for 2025-26 will further increase this figure. It was always recognised that in the first two years establishing the Institute would see significant initial investment in the resourcing of the organisation.

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

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

Specific investment powers of the Trustees

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

Going Concern

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

Reserves policy

The charity's reserves policy focuses on the level of "free reserves". Free reserves exclude restricted funds and designated funds. The recommended free reserves level is calculated annually in advance of the budget process based on the financial impact of the current risks facing the charity and is formally reviewed each year by the Trustees. The charity seeks to maintain free reserves to manage the risks to which the charity is exposed in the course of its business, including, but not limited to, safeguarding against the volatility of voluntary income.

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

Fundraising approach and performance in 2024-25

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

Last year, 65% (2024: 24%) of our donations (excluding legacies) came from our community of supporters. We greatly appreciate and recognise the importance and value of the relationship with our supporters. We ensure

our supporters are informed and inspired by the way the organisation both raises and spends its funds. We are mindful of the impact of the continuing cost-of-living crisis on our supporters and will ensure we are clear in demonstrating the impact of our work and that our fundraising targets and campaigns are appropriate. Many of our supporters take part in events to raise money through sponsorship. Where events take place in person, we have clear written contracts with suppliers and there is full transparency of the costs involved.

We are registered with the Fundraising Regulator and work to ensure that all our fundraising is carried out to recognised standards. We do not directly fundraise or market to individuals who have not signed up as supporters or agreed to receive mail from the charity with news, information and fundraising opportunities. We have a clear set of guidelines for people who fundraise on our behalf and these are sent to and agreed by the fundraiser in advance of any activity. We have had no complaints about our fundraising approach in the past year.

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

Structure, governance and management

Governing document

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

On 22 March 2007, The Memorandum and Articles of Association were amended by a special resolution to change the name of the company from Epilepsy Research Foundation to Epilepsy Research UK (as part of the merger process with the Fund for Epilepsy) and the company was registered with Companies House under this name on 30 March 2007.

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

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

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

As part of the merger with the Fund for Epilepsy in March 2007, two companies, Epilepsy Research Foundation Ltd and Fund for Epilepsy Ltd, were incorporated to protect these names, with Epilepsy Research Institute UK as sole member. Confirmation statements and dormant company accounts are submitted for these two entities to Companies House on an annual basis.

Organisation

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

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

Volunteers

We are grateful for the significant support we receive from the members of the Trustee Board and the Scientific Advisory Committee who all provide their extensive knowledge, skills and experience on a voluntary basis.

Appointment of Trustees

As set out in the Articles of Association the Trustees are appointed by the Board of Trustees. The Articles of Association provide for a minimum of seven and a maximum of sixteen Trustees, with the option to extend beyond this by ordinary resolution.

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

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

Founding Partner Trustees

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

included:

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

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

Key Strategic Partner Trustees

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

There were no such elections during 2024-25.

Trustee induction and training

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

Pay Policy for Senior Staff

The directors, who are the charity's Trustees, and the Chief Executive comprise the key management personnel of the charity in charge of directing, controlling, running and operating the charity on a day-to-day basis. All directors give of their time freely and no director received remuneration in the year. Details of directors' expenses and related party transactions are disclosed in note 11 to the accounts. The Board of Trustees, excluding the Chief Executive, review employee pay on an annual basis considering performance against objectives set and the retail price index. The pay

of the Chief Executive is usually reviewed annually by the Nominations and Advisory Subcommittee.

Risk management and disclosure

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

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

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

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

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

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

The Board of Trustees are satisfied that the major risks have been identified and processes for addressing are in place

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

Statement of Trustees' responsibilities

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

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

- Select suitable accounting policies and apply them consistently
- Observe the methods and principles in the applicable charity SORP
- Make judgements and estimates that are reasonable and prudent
- State whether applicable accounting standards have been followed
- Prepare financial statements on a 'going concern' basis unless it is inappropriate to presume that the charitable company will continue in business

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for

the prevention and detection of fraud and other irregularities.

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

Statement as to disclosure of information to auditors

In so far as the Trustees are aware at the time of approving our Trustees' annual report:

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

By order of the Board of Trustees

Professor Matthew Walker
Chair, Board of Trustees

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

FINANCIAL STATEMENTS

Opinion on financial statements

We have audited the financial statements of the Epilepsy Research Institute UK (“the charitable company”) for the year ended 31 March 2025 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement including changes in net debt and notes to the financial statements, including a significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

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

Basis of opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical

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

Conclusions relating to going concern

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

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

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

Other information

The other information comprises the information included in the Trustees' Annual Report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the Annual Report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge

obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or

- Certain disclosures of directors' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

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

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

Auditor's responsibilities for the audit of the financial statements

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

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

Capability of the audit in detecting irregularities, including fraud

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

Audit procedures performed by the engagement team included:

- Discussions with management and assessment of known or suspected instances of non-compliance with laws and regulations and fraud, and review of the reports made by management; and
- Assessment of identified fraud risk factors; and
- Holding discussions with appropriate personnel to gain further insight into the control systems

- implemented, and the risk of irregularity; and
- Performing analytical procedures to identify any unusual or unexpected relationships, including related party transactions, that may indicate risks of material misstatement due to fraud; and
- Confirmation of related parties with management, and review of transactions throughout the period to identify any previously undisclosed transactions with related parties outside the normal course of business; and
- Reading minutes of meetings of those charged with governance and reviewing correspondence with relevant tax and regulatory authorities; and
- Verifying the year-end cash at bank balances to online banking portals to verify accuracy; and
- Review of significant and unusual transactions and evaluation of the underlying financial rationale supporting the transactions; and
- Identifying and testing journal entries, in particular any manual entries made at the year end for financial statement preparation.

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

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

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our

opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control

- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charitable company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees
- Conclude on the appropriateness of the Trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern
- Evaluate the overall presentation, structure and content of the financial statements,

including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation (ie. gives a true and fair view)

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

Use of our report

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

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

STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 31 MARCH 2025

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £	Total Funds 2024 £
Income from:					
Donations and legacies	2	935,504	389,298	1,324,802	1,886,154
Grants	3	-	-	-	1,478,851
Other trading activities	4	11,110	-	11,110	3,608
Investments	5	364,471	-	364,471	226,496
Total income		<u>1,311,085</u>	<u>389,298</u>	<u>1,700,383</u>	<u>3,595,109</u>
Expenditure on:					
Cost of raising funds					
Raising Funds	6	<u>269,065</u>	<u>-</u>	<u>269,065</u>	<u>177,658</u>
Charitable activities					
Research grants committed	7	1,279,625	199,914	1,479,539	1,999,070
Other research activities	8	<u>1,084,328</u>	<u>22,120</u>	<u>1,106,448</u>	<u>914,535</u>
Total charitable expenditure		<u>2,363,953</u>	<u>222,034</u>	<u>2,585,987</u>	<u>2,913,605</u>
Total expenditure		<u>2,633,018</u>	<u>222,034</u>	<u>2,855,052</u>	<u>3,091,263</u>
Net unrealised gains / (losses) on investments	12	<u>44,269</u>	<u>-</u>	<u>44,269</u>	<u>(278,842)</u>
Net income/(expenditure) for the year		<u>(1,277,664)</u>	<u>167,264</u>	<u>(1,110,400)</u>	<u>782,688</u>
Transfers between funds	16	167,264	(167,264)	-	-
Net movement in funds for the year		(1,110,400)	-	(1,110,400)	782,688
Reconciliation of funds:					
Total funds brought forward on 1 April		<u>4,178,272</u>	<u>-</u>	<u>4,178,272</u>	<u>3,395,584</u>
Total funds carried forward at 31 March	17	<u>3,067,872</u>	<u>-</u>	<u>3,067,872</u>	<u>4,178,272</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 55 to 65 form part of these financial statements.

BALANCE SHEET

AS AT 31 MARCH 2025

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

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

Prof Matthew Walker
Chair

Judith Spencer-Gregson FCA
Treasurer

Registered company number: 4873718

Registered charity number: 1100394

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

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2025

	2025 £	2024 £
Cash (outflow)/inflow from operating activities	(1,871,875)	1,946,632
Cash flows from investing activities		
Sale of investments	550,048	-
Net purchase of investments	(250,000)	-
Income reinvested	(311,374)	(157,845)
Dividends and interest received	364,471	226,493
Net cash inflow/(outflow) from investing activities	353,145	(3,306,352)
Increase/(decrease) in cash and cash equivalents in the year	1,518,730	(1,359,720)
Cash and cash equivalents at the beginning of the year	2,197,361	3,557,081
Cash and cash equivalents at the end of the year	678,631	2,197,361
Reconciliation of net movement in funds to net cash flow from operating activities		
Net movement in funds	(1,110,400)	782,688
Deduct investment income shown in investing activities	(364,471)	(226,496)
Deduct investment gain/add (loss)	(44,269)	(278,842)
(Increase)/decrease in debtors	(82,558)	1,021,978
Increase/ (decrease) in creditors due within one year	(328,408)	490,590
Increase/(decrease) in creditors due after more than one year	58,231	156,714
Net cash from/used in operating activities	(1,871,875)	1,946,632
Analysis of cash and cash equivalents		
Cash deposits	1,886,696	1,886,696
Cash at bank	310,665	310,665
Net Cash from/used in operating activities	2,197,361	2,197,361
Cash at bank and cash in hand includes cash and short term highly liquid investments with a maturity of less than twelve months from the balance sheet date.		
Analysis of changes in net debt	As at 31 Mar 24	Cashflows As at 31 Mar 25
Cash deposits and cash at bank	2,197,361	678,631

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

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

1 ACCOUNTING POLICIES

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

a) **Basis of preparation**

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019) - Charities SORP (FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

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

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

running costs of the organisation and it is written off in the year of purchase.

c) **Incoming resources**

Income is included in the Statement of Financial Activities when the charity has entitlement to the funds, certainty of receipt and the amount can be measured with sufficient reliability. The income from fundraising ventures is shown gross, with the associated costs included in fundraising costs. Legacy income is included in the Statement of Financial Activities to the extent of cash received or a clear indication regarding amounts receivable has been given by executors. No endowments have been received in the period.

d) **Resources expended**

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

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

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

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

e) Donated services

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

g) Grants committed

All individual grants are fully provided for in the accounts in the year in which they are authorised by the Trustees whether they are for short term projects or for ones extending over a year or more. All current grants are of a maximum duration of 4 years, and all grants are covered by our cash balances, deposits and investments.

h) Pension costs

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

f) Interest receivable

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

i) Value Added Tax (VAT)

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

j) Funds

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

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

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

k) Taxation

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

l) Leases

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

2 DONATIONS AND LEGACIES

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

Donations and Legacies 2024

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

Income from fundraising events arises from events organised by the charity and its supporters.

Online advertising to the value of £66,454 (2024: £66,393) was donated as a Gift in Kind and this amount is included in "Other donations".

Legacies: The charity's policy is to accrue into the accounts all legacies notified during the year where there is sufficient evidence to provide the necessary certainty that the legacy will be received and the value of the incoming resources can be measured with sufficient reliability.

3 GRANTS RECEIVED

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

4 OTHER TRADING ACTIVITIES

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

5 INVESTMENT INCOME

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

6 COSTS OF RAISING FUNDS

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

7 RESEARCH GRANTS COMMITTED

	2025 £	2024 £
Committed as at 31 March 2024	6,314,802	5,609,511
Authorised during year (see Trustees' report)	1,715,228	2,028,835
No longer required	(235,689)	(29,765)
Paid in year	(1,856,905)	(1,293,779)
Committed as at 31 March 2025	<u>5,937,436</u>	<u>6,314,802</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 20-25. Details of all grants awarded are available on the website: epilepsy-institute.org.uk/eri/research/research-portfolio/. Grants no longer required relates to projects that were completed without the original grant being spent.

8 OTHER RESEARCH ACTIVITIES

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

Other Research Activities 2024

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

9 SUPPORT AND GOVERNANCE COSTS

	Support Costs £	Governance Costs £	Total 2025 £	Total 2024 £
Staff costs	-	63,170	63,170	31,336
Other staff costs	47,184	4,170	51,354	39,388
Office rent & facilities	61,875	5,468	67,343	49,675
Office running costs	11,159	986	12,145	29,676
IT & bank charges	46,515	4,111	50,626	36,247
Investment fees	-	35,808	35,808	25,623
Audit	-	17,390	17,390	16,200
Trustee meetings & expenses	-	12,103	12,103	12,325
Legal & professional fees	-	12,844	12,844	9,663
	<u>166,733</u>	<u>156,050</u>	<u>322,783</u>	<u>250,133</u>
Basis of allocation				
Allocated to fundraising costs	25,351	28,136	53,487	16.57%
Allocated to charitable activities	141,382	127,914	269,296	83.43%
	<u>166,733</u>	<u>156,050</u>	<u>322,783</u>	<u>100.00%</u>

Support and Governance costs 2024

	Support Costs £	Governance Costs £	Total 2024 £
Staff costs	-	31,336	31,336
Other staff costs	39,388	-	39,388
Office rent and facilities	49,675	-	49,675
Office running costs	29,676	-	29,676
IT and bank charges	36,247	-	36,247
Investment fees	-	25,623	25,623
Audit	-	16,200	16,200
Trustee meetings & expenses	-	12,325	12,325
Legal & professional fees	-	9,663	9,663
	<u>154,986</u>	<u>95,147</u>	<u>250,133</u>
	Support Costs £	Governance Costs £	Total 2024 £
Basis of allocation			
Allocated to fundraising costs	24,992	15,348	40,340
Allocated to charitable activities	129,994	79,799	209,793
	<u>154,986</u>	<u>95,147</u>	<u>250,133</u>

10 TOTAL AUDITOR'S REMUNERATION

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

11 STAFF COSTS

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

Employees receiving salaries within the following bands:

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

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

	2025	2024
Charitable activities	11	8
Fundraising	2	1
Governance	1	1
	<u>14</u>	<u>10</u>

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

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

12 INVESTMENTS

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

Analysis of investments:

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

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

13 DEBTORS

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

	2025 £	2024 £
Research grants not yet claimed	2,878,651	3,314,248
Accruals	29,364	27,784
Other creditors	180,735	75,126
Due within 12 months	3,088,750	3,417,158
Research grants due after 12 months	3,058,785	3,000,554
	<u>6,147,535</u>	<u>6,417,712</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 #Every1EndingEpilepsy, a programme with the vision to radically advance the treatment and prevention of epilepsy, including the transition costs of becoming an institute.

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

Unrestricted Funds 2024

	Designated Funds			Total Unrestricted Funds
	Research Fund 2024 £	#Every1Ending Epilepsy 2024 £	General Fund 2024 £	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>

16 RESTRICTED FUNDS

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

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

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

Restricted Funds 2024

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

17 ANALYSIS OF NET ASSETS BETWEEN FUNDS

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

Analysis of net assets between funds 2025

	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total Funds 2024 £
Total assets	10,595,984	-	10,595,984
Current liabilities	(3,417,158)	-	(3,417,158)
Creditors falling due after more than 1 year	(3,000,554)	-	(3,000,554)
	<u>4,178,272</u>	<u>-</u>	<u>4,178,272</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 2025, there was an extension to a co-funded award with Angelini Pharma of £199k was made to Trustee Professor Mark Richardson as lead applicant. This was awarded via the Institute, but the whole amount was funded by Angelini Pharma with monetary contribution from the Institute. Also in 2025, there was one new award where Institute President Helen Cross is a project collaborator. This is based at the University of Glasgow and entitled 'VISDOM-AI: Video-based Infantile epileptic Spasms Detection from bOdy Movements using AI'. As only funded in March 2025, no payments were paid out on the award during 2024-25. For these awards, no direct salary or salary contribution was paid for the Trustee/ President's involvements.

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

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

19 LEASE COMMITMENTS

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

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

April 25 - Mar 26 £50,102

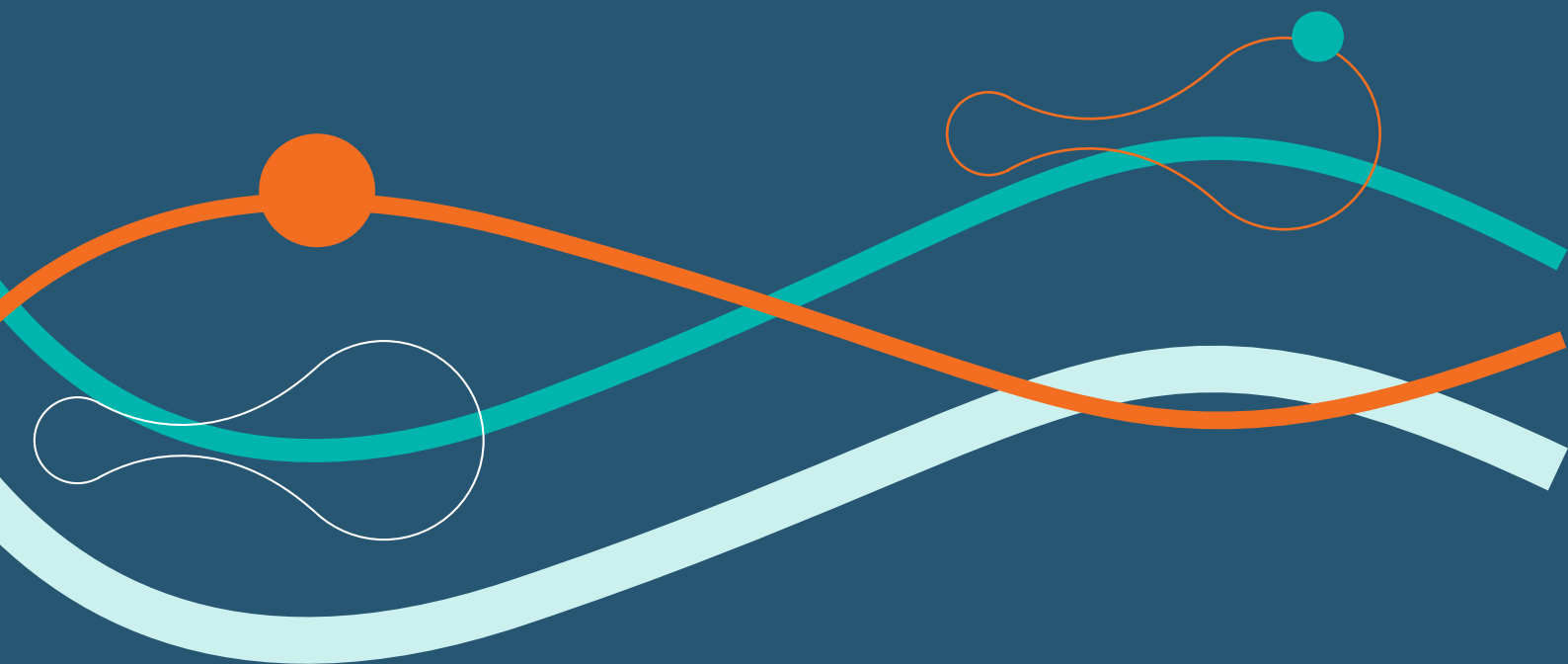
20 STATEMENT OF FINANCIAL ACTIVITY FOR THE YEAR ENDED 31 MARCH 2024 (PRIOR YEAR)

(Including the Income & Expenditure Account)

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

TOGETHER, WE WILL RADICALLY ADVANCE RESEARCH INTO EPILEPSY

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



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

John, supporter

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

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

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



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