Brainwave The Irish Epilepsy Association
T/A Epilepsy Ireland

Reports and Financial Statements
for the financial year ended
31 December 2024

BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND

REPORTS AND FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2024

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BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND

DIRECTORS AND COMPANY INFORMATION

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BANKERS	Allied Irish Banks plc Bank of Ireland Permanent TSB
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CHARITY NUMBER	CRA (Charities Regulator): 20010553 CHY (Revenue): 6170
COMPANY REGISTRATION NUMBER	77588

The directors present their annual report and the audited financial statements of the company for the financial year ended 31 December 2024.

OBJECTIVES AND ACTIVITIES

Established in 1966, Brainwave The Irish Epilepsy Association CLG, trading as Epilepsy Ireland, is the national organisation dedicated to supporting and representing people with epilepsy in Ireland, along with their families and carers.

About Epilepsy

Epilepsy refers to a group of neurological disorders characterised by recurrent, unprovoked seizures resulting from abnormal electrical activity in the brain. It affects approximately 45,000 individuals in Ireland, including an estimated 10,000 to 15,000 children.

In most cases, epilepsy is a manageable condition. Currently, up to 70% of individuals can achieve seizure freedom through appropriate medication and self-management strategies. In certain instances, surgical intervention or neurostimulation therapies may also be employed to support seizure control.

Each year, around 2,000 new epilepsy diagnoses are made in Ireland. Approximately 15,000 individuals live with uncontrolled seizures. For this group in particular, epilepsy can lead to a persistent and often hidden disability, impacting all facets of life—education, employment, family and social engagement, cognitive and psychological health, and independent living. In addition to the direct effects of seizures and medication side effects, many people also face social stigma related to the condition. The financial impact of epilepsy is also considerable. Across Europe, over €15 billion is spent annually on epilepsy care. In Ireland, the total cost—both direct and indirect—is estimated by Epilepsy Ireland at approximately €584 million each year, or nearly €15,000 per person.

Epilepsy also carries an increased risk of mortality due to factors such as status epilepticus (prolonged seizures), injuries or trauma, and underlying medical conditions. One of the leading causes of epilepsy-related deaths is Sudden Unexpected Death in Epilepsy (SUDEP), a poorly understood and fatal complication of the disorder.

The role and strategy of Epilepsy Ireland

Epilepsy Ireland's Vision is to achieve a society where no person's life is limited by epilepsy. Our Mission is to empower all those affected by epilepsy to achieve their full potential by providing high-quality community-based support and education, raising public awareness, conducting effective advocacy and supporting research.

For almost 60 years, our efforts have been firmly rooted in lessening the burden of epilepsy for those affected by the condition and their families. Our current Strategic Plan (2022–2026) outlines six overarching strategic aims, which alongside our vision and mission, guide all of our organisational activities during this period:

1. Empowering people with epilepsy through support and education.
2. Centring people with epilepsy and their families in the work of Epilepsy Ireland.
3. Working collaboratively to improve the care of people with epilepsy and knowledge of the condition.
4. Transforming perceptions of epilepsy and public policy relevant to the condition
5. Increasing and diversifying our income.

6. Demonstrating the highest standards of governance and ensure the structures are in place to meet objectives.

These strategic aims are further detailed through 13 key objectives, which shape our annual operational plans, budgets, and performance monitoring. These objectives also provide the framework for this Directors' Report.

The plan sets out an ambitious and comprehensive roadmap for the continued development and enhancement of our organisation, services, and activities. It aims to meet the growing demand for support services and reflect the evolving needs of the epilepsy community, with the ultimate goal of achieving meaningful, positive outcomes for those we serve.

The year 2024 marked the third year of our Strategic Plan. Further details on our work during the year, including key activities, challenges, and accomplishments under each of the six strategic aims and 13 core objectives, are presented in the *Achievements & Performance* section that follows.

ACHIEVEMENTS & PERFORMANCE

Support and Education

Strategic Aim 1: *Empower people with epilepsy through support and education*

1.1 Provide the highest quality support and education services.

Our support and education services for people with epilepsy, as well as their families and carers, are central to the work of Epilepsy Ireland. Access to accurate information and effective education is essential to overcoming the fear, stigma, and misunderstanding that often surrounds the condition. Our services aim to empower individuals at every stage of their epilepsy journey, while also extending to health professionals, schools, employers, and the wider public.

Our offerings include one-to-one support, educational programmes, individual and group-based self-management programmes, outreach services in both community and hospital settings, support groups, seminars and workshops, a variety of resources and publications, and personal advocacy support.

These services are delivered by a nationwide team of 11 Community Resource Officers (CROs) located in Dublin, Cork, Galway, Shannon, Kilkenny, Killarney, Tullamore, Letterkenny/ Sligo, and Navan. They are supported by our Youth Resource Officer and National Information Officer, and collectively work to address the needs of individuals in their local communities. In addition, an Advanced Nurse Practitioner (RANP) post, funded by Epilepsy Ireland and based in Beaumont Hospital, provides specialist clinical support and expertise.

In 2024, demand for our services remained high, with a total of 20,000 contacts recorded throughout the year (2023: 19,975). This figure includes 9,757 individual contacts made via phone, email, Zoom, or in-person meetings (2023: 9,533), and 10,243 people who accessed group-based support and training services offered online and in-person (2023: 10,442).

A key component of our support offering is the *Living Well with Epilepsy* programme, targeted at adults and parents who have recently received an epilepsy diagnosis. Commonly referred to as the "toolkit", this programme is delivered by our CRO team and aims to equip participants with the knowledge and skills required to better understand and self-manage their condition. In 2024, 283 individuals took part in the programme (2023: 233).

Group-based supports have long been a cornerstone of our service. In 2024, 68 group events were held, including support groups for adults living with epilepsy, parents of children with epilepsy, and sessions offered as part of our Young Epilepsy Programme (see section 1.2 below).

These group sessions provide a safe and supportive environment in which individuals living with epilepsy, or those supporting someone with the condition, can connect with others who share similar experiences. Facilitated by CROs, these supports are delivered both online and in-person, with in-person groups primarily taking place in larger population centres. To further enhance accessibility and encourage participation, national online support groups were made available throughout 2024, allowing individuals from across the country to connect. In addition, parallel sessions were introduced during the year, offering both morning and evening options to accommodate different schedules. These developments are set to continue in 2025.

Following its integration into the International Epilepsy Congress (IEC) in Dublin in 2023, our standalone National Conference returned in 2024. Building on the success of the IEC, the 2024 event was held alongside the Irish Epilepsy League's annual conference for epilepsy professionals, enabling us to assemble an exceptional panel of national and international speakers. Notable contributors included Prof. Tony Marson (*The First Epileptic Seizure*), Dr. Sophia Varadkar (*Developments in Diagnosis and Treatment of Complex Childhood Epilepsies*), Prof. David Henshall (*Epilepsy in dogs as a way to trial a new gene therapy*), Dr. Cristina Ruedell Reschke (*How Epilepsy Clocks are Ticking*), Dr. Melissa Alves Braga de Oliveira (*Myths and Truths About Sleep*), and Sinéad Murphy, ANP (*Women with Epilepsy: The Need-to-Knows*). The conference was attended by 150 people.

In addition to the national conference, several other educational events were organised throughout the year on topics including Nutrition and Epilepsy, Mindfulness, and Memory and Study Skills.

Six Joint Epilepsy Education Sessions for adults newly diagnosed with epilepsy were co-delivered by our CROs working alongside HSE Advanced Nurse Practitioners (2023: 6). These events have proven to be a successful and effective model of collaboration between EI and HSE professionals. Four sessions for parents and guardians of children with epilepsy were also held (2023: 2), and these services will continue in 2025.

Epilepsy Ireland continues to fund an Advanced Nurse Practitioner (RANP) role at Beaumont Hospital with a specific focus on the care of women with epilepsy. Outreach clinics are also provided at the National Maternity Hospital, the Rotunda, the Coombe, and Our Lady of Lourdes Hospital in Drogheda. Of the total individual contacts recorded in 2024, 1,127 were with the RANP (2023: 1,111). In addition to direct clinical care, the RANP supports our services team, co-facilitates online education sessions with CROs, and contributes to the review and development of EI's informational materials.

Epilepsy Ireland also works closely in supporting professionals whose work brings them into contact with people living with epilepsy. This includes healthcare workers, educators and others. Our resources for professionals include publications such as *Education Information Pack – An Epilepsy Resource for Pre-schools, Schools, and Colleges* and *Epilepsy in the Workplace*.

In addition, we deliver tailored epilepsy awareness sessions to schools, healthcare institutions, workplaces, and other settings where a need is recognised. In 2024, a total of 130 awareness sessions were held, reaching 2,896 attendees (2023: 152 sessions / 3,731 attendees).

1.2 Identify and fill gaps in epilepsy service needs.

Following the introduction and development of several initiatives in recent years to increase engagement with young people and children living with epilepsy, a significant milestone was achieved in 2024 with the appointment of our first-ever Youth Resource Officer (YRO) and the formal establishment of our *Young Epilepsy Programme* (YEP).
Managed and co-ordinated by the YRO, the Young Epilepsy Programme offers a series of tailored events and group supports for young people with epilepsy, ranging in age from 8 to 24. The programme includes the following key initiatives:

- *Get ChARTy (8–12-year-olds)*
  These online sessions provide an informal space for children with epilepsy to connect with others while engaging in creative art activities. The sessions were once again facilitated by Creative Art Therapist Nichola Mooney alongside our YRO.
- *Teen Time (13–17-year-olds)*
  This online event offers a supportive and safe environment for teenagers with epilepsy to share their personal journeys and challenges with others who understand their experience.
- *Young Adult Meetups (18–24-year-olds)*
  Young adulthood brings its own unique challenges, such as exams, increased independence, starting careers, or forming new relationships—life events that can impact a person's epilepsy. This event allows attendees to share their experiences, learn from others, and develop a greater sense of support through shared understanding.

We also continued to offer workshops for siblings of children with epilepsy (aged 8–12). These sessions provide a chance to engage in fun, interactive online activities while also creating space to talk about any concerns participants may have regarding their sibling's epilepsy. The workshops aim to reduce feelings of isolation, ease anxiety, and help children better understand their sibling's condition.

Almost 70 sessions were held in total across all of the above services. Participants can progress through each stage of the YEP as they grow older, building lasting connections with peers and understanding that they are not alone. The programme aims to increase awareness among young people about the importance of self-management in epilepsy, thereby improving their quality of life over time. At its core, the programme encourages young people to recognise that while epilepsy is a part of their life, it does not have to define it.

Additionally, helping young people to be open and comfortable with their condition from an early age contributes to greater public awareness and helps to reduce stigma around epilepsy over the longer term.

The YRO also facilitates group supports for siblings of children with epilepsy and will continue to expand the Young Epilepsy Programme in the coming years. The appointment of the YRO was made possible through a grant from Angelini Pharma for the period 2024–2026.

One of the highlights of the year was our annual *Family Fun Day*, co-ordinated by the YRO and held at Dublin Zoo in July. The event provided a relaxed, fun opportunity for many of the children and young people who engage with YEP services, as well as our wider membership, to meet in person. There were 156 attendees on the day (2023: 150), and the event was an enjoyable and memorable experience for families and staff alike.

Building on its 2023 launch, usage of our *Epilearn* e-learning resource continued to grow in 2024. The app features a single, comprehensive module offering bitesize information on epilepsy, presented through structured learning pathways. These include videos, quizzes, and practical exercises, covering topics such as an introduction to epilepsy, seizure types, seizure triggers, medications, and seizure safety. By year-end, there were 470 registered users of the app. In 2025, we plan to increase promotion of the app and introduce a new learning pathway to further enhance the platform.

In response to another identified needs gap, July 2024 saw the launch of a pilot reimbursement scheme for seizure detection devices. This long-term aspiration of the organisation was developed to support individuals with epilepsy in purchasing seizure detection alarms - devices that can alert a caregiver when a seizure occurs. For many living with epilepsy, the alarms can be unattainable due to the costs involved.

Supported through donations made in memory of the late Louise Young, the scheme was piloted at one hospital site (Beaumont Hospital), providing reimbursement for one specific device—the Empatica Embrace 2. A referral and reimbursement process was put in place, and by the end of the year, plans were in place to expand the scheme to all hospital sites in early 2025.

We look forward to further establishing the scheme, for example by adding a wider range of devices, and we hope that it will benefit hundreds of people living with epilepsy in the years to come, serving as a lasting legacy in memory of Louise Young.

Membership and Engagement

Strategic Aim 2:
Centre people with epilepsy and their families in the work of Epilepsy Ireland

2.1 Develop a new volunteering and engagement approach that is centered on lived experience.

This is a key strategic objective for our organisation, ensuring that the Board, management, and staff remain consistently focused on understanding the needs and lived experiences of the epilepsy community, and shaping our work accordingly.

In 2024, we officially launched the Epilepsy Ireland Service-User Consultation Group.
Originally established by the Board in 2023, the group consists of 11 members who have used our services, been involved in our work, or volunteered in the past. Its purpose is to provide feedback, input, and new ideas on Epilepsy Ireland's operational activities, helping to ensure that our work continues to reflect the needs of people with epilepsy and their families in line with our vision, mission, and values.

The group met three times in 2024, with discussions covering the topics of: future advocacy priorities; National Conference agenda; EI's membership structure; planning for International Epilepsy Day 2025; and services planning.

The group has played a pivotal role in shaping these initiatives, as well as offering valuable feedback ahead of broader consultations with the wider community. We extend our sincere thanks to all group members for their commitment and contributions throughout 2024. The group will continue its work in 2025, with a planned review of its membership to ensure a full range of voices from within our community are represented.

In October 2024, we conducted our annual Service User Consultation Survey. This survey offered service users and volunteers who engaged with us during the year an opportunity to provide feedback across all aspects of our work—support services; training and education programmes; awareness and advocacy campaigns; and activities relating to epilepsy research. Promoted across all our communication channels, 106 responses were received.

The survey was a valuable exercise, offering thoughtful insight into various areas of our work. We were especially encouraged by the overwhelmingly positive feedback. 98% of respondents said they would recommend Epilepsy Ireland to others with similar needs, while 95% rated their experience with Epilepsy Ireland as either very positive (85 respondents) or positive (16 respondents).

These figures closely mirror the results from 2023. We plan to conduct the survey again in 2025 to continue tracking and improving the experiences of all those who engage with our organisation.

As a membership-based organisation, Epilepsy Ireland offers a range of one-, three-, and five-year membership packages. Our members strengthen our collective voice, and we encourage everyone with an interest in epilepsy to consider becoming a member.

In late 2023, we initiated a review of our current membership structure, which was first introduced in 2018. This work continued through 2024 and involved an examination of membership within similarly sized membership-led organisations, as well as reviewing membership-related clauses within the organisation's constitution. With the review ongoing, the Board agreed to temporarily suspend three- and five-year membership options, with the expectation that this work will be completed and a new membership model introduced in 2025.

Volunteering

While our core services are delivered exclusively by paid staff, volunteers play a pivotal role in supporting our mission - whether through raising awareness of epilepsy (e.g. sharing personal stories and participating in media engagements), supporting advocacy initiatives, or contributing to epilepsy-related research.

Volunteer-led fundraising is also a critical part of our success. This includes organising events, participating in Epilepsy Ireland–led campaigns and collections, and representing us in marathons, challenges, and other initiatives. Each year, we are fortunate and grateful to have the support of hundreds of fundraising volunteers - see section 5.1 for further details.

The Volunteer of the Year award is presented annually to individuals or groups who have made exceptional contributions to the work of Epilepsy Ireland. It also helps to highlight the vital role that volunteers play within our organisation. The process of selecting recipients is a reminder of how fortunate we are to have the support of such dedicated and passionate people, all committed to raising both awareness and funds in pursuit of a society where no person's life is limited by epilepsy.

In 2024, we were delighted to name the McCarton family from Tallaght as our Volunteers of the Year. As part of a now-annual fundraising tradition, the McCartons open their home each Good Friday for a coffee morning to raise funds for Epilepsy Ireland. They began this initiative following Mileaha's and Graham's epilepsy diagnoses in recent years. The entire local community gets involved in these events, with local businesses supporting raffles for the coffee morning and the most incredible looking home baking keeping the hunger away for all those in attendance. Since they first began, the McCarton family have raised almost €10,000 for Epilepsy Ireland. While the funds raised are incredibly important to our work, the community awareness generated through these events is equally invaluable. We extend a heartfelt thank you to the entire McCarton family as well as neighbours who help organise this remarkable annual event. The McCartons were presented with their award at the 2024 National Conference.

Collaboration, Care and Knowledge

Strategic Aim 3:
Work collaboratively to improve the care of people with epilepsy and knowledge of the condition.

Epilepsy Ireland works collaboratively with a wide range of stakeholders - including state bodies, healthcare and education professionals, and the medical and scientific community - to improve care for people with epilepsy and to enhance understanding of the condition. Below, we highlight the key activities carried out in 2024 under each of the four associated objectives of our Strategic Plan.

3.1 Advance a community-based, patient-centred and collaborative epilepsy model of care in conjunction with HSE and other stakeholders.

Epilepsy Ireland recognises its important role in the development of epilepsy services in Ireland and has a long-standing record of successful collaboration with HSE services to enhance and expand service provision.

Our strategic objective of advancing a community-based, patient-centred model of care is closely aligned with the HSE's *Sláintecare* strategy. This national strategy aims to reform health services through improved integration and coordination across care settings, early intervention, and person-centred care tailored to individual needs. In applying these principles to epilepsy care, our community-based services play a vital role in the broader support system for people living with epilepsy.

One of the ways we are advancing this goal is through the Joint Education Sessions described in Section 1.1. Initially funded by the *Sláintecare* Integration Fund, we have continued to deliver these sessions in partnership with HSE services even after the funding concluded. The programme, aimed at newly diagnosed adults and parents of newly diagnosed children, is co-delivered by epilepsy specialist nurses and Epilepsy Ireland CROs. We believe this collaborative initiative is an excellent model of early intervention, offering vital education and support at a crucial time. In 2024, 10 such sessions were held (2023: 8).

As part of our mid-point Strategic Plan review in July 2024, the Board decided to focus the organisation's efforts under this objective on two specific goals: promoting epilepsy in primary care; and advocating for the inclusion of epilepsy in the HSE's Chronic Disease Management Programme (CDMP).

To support the first goal, we published our GP Consultation Guide in partnership with the Department of General Practice at UCC. The guide is intended to support improved communication between GPs and patients with epilepsy and to foster stronger collaborative relationships.

The second goal - achieving inclusion of epilepsy in the CDMP - is now one of our core advocacy priorities (see Section 4.1) and will be central to our engagement with the new government and Oireachtas.

In pursuit of this objective, and continuing our collaboration with UCC, a large GP practice in the Midlands agreed to manage their epilepsy patients under a similar framework to that used for other conditions in the CDMP. This pilot initiative will generate valuable data and insights from both patients and GPs to help inform our advocacy efforts in 2025 and beyond.

We continue to maintain strong links with epilepsy specialist services across the country, both paediatric and adult. This includes our continued funding of the Registered Advanced Nurse

Practitioner (RANP) for Women with Epilepsy, based at Beaumont Hospital (see Section 1.1), as well as ongoing engagement with the National Epilepsy Clinical Care Programme, the PREVENT Programme and a range of formal/ informal professional networks.

Other collaborations during 2024 aimed at improving care for people with epilepsy and knowledge of the condition included:

- Ongoing work with a variety of stakeholders on the health information and education needs of women with epilepsy (See Section 3.3).
- Close collaboration with the Irish Epilepsy League on the setting of new advocacy priorities.
- Participation in conferences and events hosted by other organisations such as Dravet Syndrome Ireland, Cavernoma Ireland and TSC Ireland.
- The launch of a new healthcare professional (HCPs) newsletter designed to strengthen communication between Epilepsy Ireland and HCPs and keep them informed of service developments that may benefit their patients.
- Presentation at the Irish Epilepsy League's Annual Expert Day.
- Launch of the pilot device reimbursement scheme in close collaboration with HCPs (see Section 1.2).
- Collaboration on specific awareness and advocacy campaigns with international organisations including SUDEP Action, the Infantile Spasms Awareness Network, and the International Bureau for Epilepsy; and with a variety of national bodies such as the Disability Federation of Ireland, the Neurological Alliance of Ireland, OACS Ireland, and others.
- Joint efforts with research institutions on epilepsy-related projects and events, including RCSI (FutureNeuro), DCU, and others as detailed in Section 3.4.
- Continued participation in the HPRA's Patient Forum and the Department of Health's Valproate Stakeholder Group.

3.2 Provide relevant and appropriate training and education services for professionals and others involved in the care and welfare of PWE.

Since 2009, Epilepsy Ireland has provided a training programme in Epilepsy Awareness & the Administration of Buccal Midazolam (BM) to health and allied health professionals. Participants include healthcare workers, education staff such as teachers and SNAs, bus escorts, employers and employees working alongside people with epilepsy, community workers, facilitators of extra-curricular activities in the community, and others.

Buccal Midazolam is an emergency rescue medication administered by caregivers in the community to stop a seizure once it has begun. It plays a vital role in preventing seizures from escalating, reducing hospitalisations, and minimising disruption to a person's daily life. Our programme educates participants on epilepsy, the role of rescue medication, and the correct administration of BM.

Training is delivered by Epilepsy Ireland's training team and CROs, in line with the guidelines of the Joint Epilepsy Council of the UK and Ireland and updated ESNA (Epilepsy Specialist Nurses Association) 2019 guidelines. On completion, participants receive a certificate valid for two years. Training is offered both online and in-person. In-house training sessions are also provided.

The programme has grown into a core part of our service. All trainers have completed 'train the trainer' instruction and undertake biannual refresher training through Quarriers, the Scottish Epilepsy Centre. In 2024, a total of 3,114 professionals participated across 215 sessions (2023: 2,791 professionals / 214 sessions). Notably, in 2024, we became the preferred training provider of the Health Information and Quality Authority (HIQA), which now signposts organisations and nursing homes to avail of our training.

New content was added to the programme in 2024 on vagal nerve stimulation (VNS) and the administration of rectal paraldehyde.

In addition to the formal training programme, our CROs delivered BM information sessions for parents and family carers in all regions. These sessions aim to ensure carers can correctly administer this commonly prescribed medication. In 2024, 52 sessions were held for 209 parents/carers (2023: 43 sessions / 183 attendees).

Epilepsy awareness talks also continued in schools, community organisations and workplaces both online and in-person. 130 total sessions were held across all settings with 2,896 attendees (2023: 152 sessions/ 3,731 attendees).

Additional bespoke training sessions were delivered in several notable institutions during the year, including The Houses of the Oireachtas; The Office of the Attorney General; RCSI (for GP students) and HIQA. Toward the end of the year, a special session was delivered for Irish Rail staff at Connolly Station, with plans in place to roll out this training to additional staff and stations in 2025.

3.3 Commission, fund and collaborate with research partners to increase knowledge about Epilepsy, its causes, effects and management.

Since launching our research funding scheme in 2009, Epilepsy Ireland has invested over €1.5 million in epilepsy research. This represents a major commitment for an organisation of our size and has only been possible thanks to the ongoing support of donors and fundraisers nationwide. In total, we have supported 23 high-quality, high-impact Irish research projects across basic science, clinical, psychosocial, genetic, and health services research.

Nearly all our research investments are made through co-funding agreements with state research funders. Historically, most of our projects have been funded through the Joint Funding Scheme (JFS), operated by the Health Research Board (HRB) and Health Research Charities Ireland (HRCI). Under this scheme, applications are funded 50% by the HRB and 50% by participating charities, including Epilepsy Ireland. While we did not participate in the most recent JFS round in 2023 due to the high number of active projects at the time, we plan to re-engage in the next round expected to open in mid-2025.

In recent years, we've also partnered with the Irish Research Council (IRC) through its Enterprise Partnership Scheme (EPS). This scheme supports postgraduate and postdoctoral researchers working in collaboration with enterprise partners like Epilepsy Ireland, with IRC funding two-thirds of costs and the partner funding the remainder. In late 2023, we agreed to partner on two applications made through the 2023/2024 round of the EPS but unfortunately, neither project was ultimately funded by the IRC in 2024. Although a new EPS call was anticipated in late 2024, it was delayed to Q1 2025 due to the merger of IRC and Science Foundation Ireland, forming the new agency, Research Ireland. Ahead of the call, we received a large number of expressions of interest and have committed to supporting a record four applications if funded by Research Ireland.

While we made no new research investments in 2024, we continued to support seven ongoing projects and we look forward to supporting new research through both the EPS and the JFS in 2025 and 2026.

Ongoing projects in 2024 were:

- *Health information and education resources for women with epilepsy from preconception to postpartum*
  Dr Aisling Walsh, RCSI (through HRB APA awards)

- *Predicting and monitoring outcomes in Autoimmune Encephalitis*
  Prof. Norman Delanty, RCSI (through HRB/ HRCI JFS)

- *Long non-coding RNAs: regulators of epileptogenesis and potential targets for therapy*
  Dr Gary Brennan, UCD (through HRB/ HRCI JFS)

- *Molecular mechanisms, therapeutic targets and biomarkers for CDKL5 Deficiency Disorder (CDD)*
  Dr Omar Mamad & Erva Ghani, RCSI (through IRC EPS)

- *Circadian biomarkers in pre-clinical and clinical Dravet Syndrome*
  Dr Cristina Reschke & Radharani Benvenutti, RCSI (through IRC EPS)

- *EPIVIEWS: Exploring Patient Impact & Value in Epilepsy Wearables for Seizure Monitoring*
  Dr Rob Argent & John David Dalameiro, RCSI (through IRC EPS)

- *Epilepsy Mortality in Ireland*
  Dr Yvonne Langan, St James's Hospital/ Trinity College

When selecting research to fund, we prioritise both scientific quality and relevance to the lived experience of people with epilepsy. Our funding also helps to attract emerging researchers to the field of epilepsy and encourages new directions in epilepsy research.

These goals were clearly demonstrated in the Reschke/ Benvenutti project, which concluded in 2024. Their study identified a novel and potentially significant finding that neuroinflammatory pathways which are regulated by the circadian 'clock' may play a key role in the mechanisms leading to Dravet Syndrome. Building on these findings, the team secured additional funding from the US-based Dravet Syndrome Foundation to expand their research.

This project, initiated through relatively modest Epilepsy Ireland investment, has opened new possibilities of future treatment targets in this rare but life-limiting condition. Dr Benvenutti's work stands as a powerful example of how early-stage, targeted support can lead to significant advances and international recognition.

We wish Drs Reschke and Benvenutti continued success in their future work, and we extend sincere thanks to our donors and supporters, whose contributions make these research investments possible.

Epilepsy Ireland contributes to research not only through funding but also by collaborating in non-financial ways, and in 2024, there were several notable developments.

One innovative new project, led by Prof. Alan Smeaton at Dublin City University (DCU), aims to develop wearable sensors for dogs with the ability to detect seizures. The project explores whether a dog's behavioural responses to a pre-seizure scent can be captured in real time using wearable technology. Through machine learning, these responses could be analysed to alert a person with epilepsy to an impending seizure, giving them vital time to seek assistance or move to a safe space, potentially reducing the risk of seizure-related injuries. The research builds on earlier work into seizure-detecting dogs, including Epilepsy Ireland–funded research by Dr. Neil Powell at

Queen's University Belfast. This project has received €492,000 in funding from Research Ireland and involves collaboration between Epilepsy Ireland, the Insight SFI Research Centre for Data Analytics at DCU, Irish Dogs for the Disabled, and Beaumont Hospital.

We also partnered on the "My Moving Brain" initiative throughout 2024. Led by FutureNeuro, this project aims to promote awareness of brain health and wellness, while encouraging inclusive participation in sport for individuals living with epilepsy and other neurological conditions across Ireland.

A central message of the project is that epilepsy should not be a barrier to participation in sport. However, we continue to hear from individuals who have been excluded from sporting activities simply due to misconceptions or a lack of understanding about epilepsy. In many cases, straightforward adjustments and basic awareness can enable full participation.

Through a series of regional workshops, the project brings together individuals with epilepsy, families, caregivers, sports clubs, coaches, teachers, patient organisations, clinicians, researchers, and members of the public to identify these barriers and explore practical ways to enhance inclusion in sport and physical activity. The first workshop was held in Dublin in November 2024 and featured powerful contributions from Epilepsy Ireland volunteers Emma Beamish and Dr. Michael McKillop MBE. Both spoke about their journeys with epilepsy and how the condition did not prevent them from competing in sport at the highest levels. Planning for the second workshop, due to take place in Cork, was well underway by the end of the year.

Communicating research is another important part of our work in this area, helping to inform and connect the epilepsy community with ongoing scientific developments. Throughout 2024, we supported several researchers by facilitating connections with people with epilepsy through our communication channels. This included the *EPIKNOW* project, co-funded by Epilepsy Ireland, which made strong progress during the year in evaluating existing information and education resources for women with epilepsy, and in identifying and prioritising their information needs. We also provided advice and insights to researchers developing project proposals, helping to ensure that upcoming studies reflect the real-life experiences and needs of those affected by epilepsy.

In collaboration with FutureNeuro, we also planned a special in-person, research-themed event for early 2025. This event will spotlight the importance of epilepsy research and showcase several significant projects underway in Ireland, including those funded by Epilepsy Ireland.

Encouraging and supporting patient and public involvement (PPI) in research remains a key objective. In 2024, we continued our engagement with Dublin City University through their PPI Ignite network, which promotes meaningful involvement of patients and the public in shaping research priorities and processes.

3.4 Promote improved awareness, knowledge and understanding of SUDEP and advance strategies to reduce the risk and incidence of epilepsy deaths.

SUDEP (Sudden Unexpected Death in Epilepsy) refers to when a person with epilepsy dies suddenly and without an obvious cause e.g. injury, drowning, or another known medical reason. There may or may not be evidence of a seizure, and it often occurs during sleep. While not fully understood, known risk factors include having uncontrolled or frequent seizures, particularly generalised tonic-clonic seizures. Lifestyle-related risks, such as poor medication adherence, alcohol use, and exposure to seizure triggers, may also contribute.

SUDEP risk management is a central focus in our education and self-management programmes, including *Living Well with Epilepsy* and our Joint Education Sessions (see Section 1.1 above). We also provide a 'Seizures and Safety' booklet and maintain an extensive online information hub at epilepsy.ie.

2024 marked a milestone in our work on SUDEP. In October, the *Epilepsy Mortality in Ireland* study, led by Dr Yvonne Langan (St James's Hospital/ Trinity College) and supported by Epilepsy Ireland, the Health Research Board, and Jazz Pharmaceuticals, published Ireland's first findings on SUDEP incidence.

Key findings from the study include:

- 33 cases of definite SUDEP identified from 2019 coroners' records
- This included 21 males and 12 females
- The age range of those who died ranged from 9 – 81 years old. The median age was 45.

Using established prevalence data, the study calculated an annual SUDEP incidence rate of 1 in 1,400. This important data provides greater clarity for people with epilepsy and clinicians, enabling better-informed decisions and guiding efforts to reduce risk and improve care.

The publication coincided with SUDEP Action Day, one of our most significant awareness initiatives. To mark the occasion, we launched a new advocacy campaign calling for strategic, coordinated action to reduce the incidence of SUDEP (see Section 4.1).

With this scientific evidence now available, we are better equipped to campaign for action such as improved access to specialist care and treatments that increase the likelihood of becoming seizure-free - a key factor in reducing SUDEP risk.

Our campaign attracted strong national attention, including coverage on RTÉ Drivetime, RTÉ 6:1 News, and features with bereaved families in the Irish Independent. It was also raised and supported in the Seanad. Personal testimonies from two families affected by SUDEP, shared on our website and social media, resonated widely and helped drive nearly 24,000 website visits in October.

Dr Langan is continuing her work to establish the incidence of all epilepsy related deaths including those resulting from status epilepticus, injury, drowning, and other causes. This next phase is expected to conclude in 2025 and will provide a fuller picture of epilepsy mortality in Ireland and amplify our calls for action.

Since 2015, Epilepsy Ireland has partnered with UK charity SUDEP Action on the Epilepsy Deaths Register for Ireland (EDRI). This secure platform allows families and professionals to record details of epilepsy-related deaths. The register supports international research efforts and helps improve understanding of SUDEP and related risks. As part of SUDEP Action Day 2024, we encouraged bereaved families to submit details to the register, resulting in 11 new submissions.

We also promoted participation by Irish healthcare professionals in an international study led by Prof. Rohit Shankar of the University of Plymouth Medical School. The study explores clinicians' experiences of communicating about SUDEP, examining practices, challenges, and barriers across different countries. Nearly 40 Irish professionals contributed to the research.

We continued our collaboration with SUDEP Action throughout the year, particularly in preparing for the introduction of their evidence-based *SUDEP and Seizure Safety Checklist* to Ireland via epilepsy.ie. The tool supports clinician-patient discussions on SUDEP risks and safety strategies. Thanks to the Corrigan family's *Cycle for Shane* fundraiser in 2022, we were able to establish a development group in 2024 to help bring this resource to Ireland. Rollout will follow the completion of an upgrade to the existing UK checklist and is anticipated in 2025.

Advocacy, Campaigns and Communications

Strategic Aim 4:
Transform perceptions of epilepsy and public policy relevant to the condition.

4.1 Use awareness and advocacy campaigns to create positive change for people with epilepsy.

We aim to transform perceptions of epilepsy through awareness-raising and advocacy campaigns that have a real impact on the lives of people living with the condition.

International Epilepsy Day, held each February, is our key public awareness opportunity. In 2024, we built on previous efforts to promote the seizure first-aid message of *Time, Safe, Stay* with a campaign centred around the idea that while thousands of words have been written about epilepsy, just three are essential in an emergency. The campaign featured:

- Broadcast and video-on-demand ads on SKY TV.
- Digital radio ads across national and local stations.
- Print and online ads in outlets like the *Irish Times*, *Irish Independent*, *breakingnews.ie*, *Joe.ie*, and *Her.ie.*
- Digital billboards in shopping centres in Dublin, Cork, and Galway
- Extensive media coverage of the key message and personal stories of living with epilepsy including in the *Irish Examiner*, *Irish Farmer's Journal*, *Virgin Media News*, and regional radio and press.
- Strong political engagement, including a campaign launch to announce the expansion of the Free Travel scheme and strong social media support from elected representatives, including the then Taoiseach who shared *Time, Safe, Stay*.

As always, our #EpilepsyDay campaign was driven by our media volunteers. In 2024, Cara, Lucy, Wayne, and Paul led the charge, with others supporting across regional and national platforms. We are grateful to everyone who shared their stories to promote *Time, Safe, Stay*, and to Connelly Partners who worked with us on the execution of the campaign. We would also like to thank Desitin Pharma who supported the campaign.

Other awareness campaigns held in 2024 included:

- National Epilepsy Week (May):
  We released new research conducted by Amárach Research on public awareness and attitudes toward epilepsy. While the findings showed strong progress in public understanding and knowledge, they also highlighted a continued need to raise awareness about seizure first aid.

  Volunteers once again shared their stories throughout the week, and we launched updated seizure first aid posters to reinforce the *Time, Safe, Stay* message. These posters are freely available on our website, with printed copies available on request.

- SUDEP Action Day (October):
  Covered in detail in section 3.4 above.

- Infantile Spasms Awareness Week (December):
  2024 marked our fourth year participating in this international awareness campaign. Infantile spasms are a rare but serious seizure disorder in babies that can cause lasting damage if not identified and treated early.

With support from a Medtronic grant, we promoted a volunteer-provided video on social media showing the subtle signs of infantile spasms. The video reached a wide audience, resulting in over 15,000 visits to our website during the week, hopefully helping to increase the awareness of the key message of *STOP* amongst new and expectant parents. STOP stands for:

- **S**ee the Signs
- **T**ake a Video
- **O**btain Diagnosis
- **P**rioritise Treatment

Our volunteer, Tania, shared her daughter Danika's story across our channels, while national media coverage included a feature in the *Irish Independent* and interviews with volunteer Fiona, discussing her son Theo's diagnosis. The campaign also featured on *Her.ie* and *Herfamily.ie*, further amplifying the STOP message to new and expectant parents.

On the advocacy front, one of our longest-running campaigns reached a successful conclusion in 2024 with the introduction of an expanded Free Travel scheme in July. The scheme allows individuals who are medically unfit to drive for at least one year to access a Free Travel pass without a means test, provided their GP certifies their condition.
Although the changes were announced in Budget 2024 (October 2023), the rollout took place across several key stages in 2024, with strong collaboration between Epilepsy Ireland and the Department of Social Protection:

- An official campaign launch coinciding with International Epilepsy Day in February
- A formal opening of the application process in May
- The full implementation of the scheme in July

Each stage attracted significant national media attention, including coverage on RTÉ and Virgin Media News. At the heart of this campaign were our media volunteers, whose stories powerfully illustrated the importance of this change. Minister Heather Humphreys publicly acknowledged Epilepsy Ireland's role throughout the process, including during a feature on the *RTÉ Six One News*.

We extend sincere thanks to all public representatives who supported this campaign, with special recognition to Minister Humphreys. From the outset of our engagement, she showed a deep understanding of the impact this issue has on people with epilepsy and a clear determination to reduce that burden. Her support has created a lasting legacy not only for people with epilepsy but for others affected by other long-term conditions that prevent them from driving.

Building on our recent advocacy successes, including the Free Travel campaign, the introduction of deferred Leaving Cert sittings, and the establishment of an inquiry into Sodium Valproate, we began preparing early in the year for a potential general election in late 2024 or early 2025. This included a consultation with our members and service users to identify the key issues they wanted us to pursue with the next Government and Oireachtas.

Through an extensive survey promoted via our website, social media, and newsletters, and with invaluable input from the Service User Consultation Group, we identified and agreed on the following new advocacy priorities:

- Improving epilepsy services and infrastructure to enhance access to specialist care and treatments for the 45,000 people in Ireland living with epilepsy.
- Enhancing Epilepsy Services & Infrastructure nationally to improve access to specialist services and treatments for the 45,000 people living with epilepsy in Ireland.
- Developing a national strategy to reduce epilepsy-related deaths through targeted actions and public health initiatives.

- Making Ireland's schools seizure-safe by ensuring all teachers receive epilepsy awareness and seizure first aid training as part of their initial teacher training.
- Ensuring Ireland's 2022 commitment to implementing the WHO Intersectoral Global Action Plan on Epilepsy and other Neurological conditions is met and a cross departmental taskforce is established to progress agreed targets.

With a general election eventually called for November 2024, we contacted the majority of candidates seeking their support for these priorities. Many of those elected have committed to working with us, and we look forward to progressing these issues with them over the coming years. Looking ahead to 2025, we expect to focus on raising awareness of these key advocacy goals and laying the groundwork for further meaningful progress in the years ahead.

A range of other advocacy activities were also undertaken in 2024, including:

- Ongoing participation in the Department of Health-led Sodium Valproate Stakeholder Group, focused on improving risk minimisation measures.
- Support for the Neurological Alliance of Ireland's "Patients Deserve Better" campaign, which continues to highlight gaps in regional access to neurology consultants,
- A formal submission to the National Centre for Pharmacoeconomics advocating for reimbursement of the anti-seizure medication Fintepla.

4.2 Increase the visibility of epilepsy and the work of Epilepsy Ireland

Epilepsy Ireland maintained a strong public profile throughout 2024, supported by the advocacy campaigns outlined in section 4.1, the successful conclusion of our Free Travel campaign, and the launch of a new campaign addressing epilepsy-related deaths (see Section 3.4). This visibility extended across both traditional media and online platforms.

Our website, epilepsy.ie, remains a vital hub for the epilepsy community to access accurate information and support. In 2024, the site recorded just over 220,000 visits, a significant increase from just under 180,000 in 2023. We continued to make targeted improvements to enhance user experience and ensure content remains relevant and accessible. Key updates during the year included:

- New content outlining our latest advocacy campaigns and objectives.
- A redesigned Contact Us form, streamlining public queries and directing them to the appropriate team member.
- Branding enhancements to strengthen Epilepsy Ireland's visual identity.
- New information sections for General Practitioners and for our Youth Resource Officer and Young Epilepsy Programme.

We will continue to monitor and develop the website in collaboration with our web developers throughout 2025.

Our social media channels remained central to our communications strategy, helping to raise awareness of epilepsy and directing audiences to our website. Facebook and Instagram were our primary platforms, with nearly 25,000 Facebook followers and almost 7,000 Instagram followers by year-end. Our presence on LinkedIn also grew steadily, reaching close to 2,000 followers by the end of 2024. We continued to build our reach on TikTok and Threads, and also established a Bluesky account late in the year. While we maintained a presence on X (formerly Twitter), our follower count remained static at approximately 5,500—reflecting a general shift away from the platform. We will continue to review our engagement strategy on X in 2025.

Our core communications activities continued as normal, including the publication of four editions of our members' newsletter, *Epilepsy News*, and regular monthly e-zines, including special issues to mark key awareness events such as International Epilepsy Day and SUDEP Action Day.

In addition, we will publish the latest edition of our Research Bulletin in early 2025, and in 2024 we launched a dedicated Healthcare Professional E-zine (see section 3.1), helping to expand our engagement with clinical stakeholders.

Fundraising & Funding

Strategic Aim 5: Increase and diversify income

5.1 Raise the funds needed to implement strategic objectives through existing streams and by embracing new techniques and technologies.

Epilepsy Ireland's main source of income continues to come from Section 39 Service Level Agreements (SLAs) with seven HSE Community Healthcare Organisations (CHOs) nationwide. In 2024, these agreements totalled €750,148, with an additional €72,719 received to meet obligations under the WRC pay agreement for Section 39 organisations. These funds contribute to staffing and operational costs associated with our support and education services.

While the additional WRC-related funding is welcome, particularly in promoting fair pay, protecting vital community services, and helping address the recruitment and retention crisis in the voluntary sector, it is important to note that cuts made to HSE funding during the post-2008 recession have never been fully restored. Combined with rising pay and non-pay costs, inflation, and growing service demand, the current level of HSE funding still falls short of covering the full cost of delivering services. This is an issue that cannot be resolved through the WRC pay deal alone.

Over the past 15 years, Epilepsy Ireland has worked to minimise funding gaps through a combination of cost-control measures, securing alternative funding (e.g. through the Scheme to Support National Organisations), and by growing non-grant income streams. In 2024, this approach helped reduce the annual funding shortfall to €58,282 (from €74,020 in 2023), a deficit covered using unrestricted income generated during the year.

We continue to collaborate with organisations such as the Disability Federation of Ireland to advocate for a more sustainable funding model that recognises both pay and non-pay costs for Section 39 organisations. Encouragingly, 2024 saw improved engagement and communication between the HSE and the sector, including a review and update of SLA Parts 1 and 2 and an examination of simplified funding models. However, uncertainty remains around how the ongoing HSE restructuring may affect future funding arrangements, reporting requirements, and relationships with new HSE regional structures.

Another important source of core funding is the Scheme to Support National Organisations (SSNO). Originally awarded in 2019, the scheme was renewed in July 2022 at an increased annual rate of €84,993 to support key organisational roles. Funding has since been extended to the end of 2025 on a pro-rata basis. We will reapply for continuation funding in mid-to-late 2025.

Total non-grant income in 2024 was €1,056,878 (2023: €905,599). This includes income from fundraising activities, donations, in-kind donations, training income, membership subscriptions, interest received and other miscellaneous income.

Fundraising performance was strong again in 2024. Income from Donations & Legacies (including donations in-kind) increased from €531,723 in 2023 to €619,091 in 2024. The positive outcome was primarily driven by unexpected legacy income of €157,500, funding of €40,587 from Angelini Pharma to support the newly created Youth Resource Officer role, and a generous donation of €90,000 received at year-end. Other corporate supports included Desitin (€5,000), Neuraxpharm

(€10,000), Citco Corporate Services Ireland (€10,000), O'Briens Wines (€10,000), and Crown Roofing & Cladding Ltd. (€5,000). A non-cash in-kind donation of €16,912 was also received from Connelly Partners in the form of donated services for their work on the International Epilepsy Day campaign. However, some income streams underperformed, including our social media campaigns, impacted by the discontinuation of Facebook fundraising in June.

Income from Other Trading Activities (which includes raffles & lotteries, campaigns & appeals, and fundraising events) increased slightly from €139,409 in 2023 to €145,615 in 2024. This includes the Time For A Break monthly draw, the annual members' raffle, and the *45 for Epilepsy* challenge which invited participants to run or walk 45km across a week, in recognition of the 45,000 people living with epilepsy in Ireland. Now in its second year, the challenge raised a fantastic €21,539.

We were also honoured to be selected by Peter Mark as their charity partner for the 2024 Petermarkathon. From October 21st–28th, their 69 salons nationwide ran creative and energetic fundraising events, while also helping raise awareness of epilepsy among their clients. Although the proceeds were received in 2025 and are not included in these financial statements, we are delighted to confirm that €93,209 was raised. A heartfelt thank you to the entire Peter Mark team for their outstanding support.

Income from our training programme in epilepsy awareness and the administration of Buccal Midazolam (See Section 3.2 above) is another vital source of unrestricted income. This amounted to €228,765, an increase from €199,730 in 2023.

In 2024, we also took important steps to improve our long-term fundraising capacity and infrastructure. The Board approved the creation of a new Corporate and Trusts Fundraising Executive role and initiated a comprehensive review of our CRM systems to ensure they remain fit for purpose across the organisation, including in fundraising. Both of these actions were in progress at year end, alongside work to implement a new fundraising platform on our epilepsy.ie website.

As in previous years, we were incredibly grateful for the unwavering support of the epilepsy community and the wider public in 2024. Our work simply would not be possible without the generosity, dedication, and passion of the thousands of individuals across the country who volunteer their time and energy to fundraise on our behalf. To each and every person who supported Epilepsy Ireland, whether through a personal challenge, a community event, or a quiet act of kindness - thank you! Your fundraising doesn't just raise money, it helps deliver vital services, raise awareness, fund research, and advocate for real policy change. As we hope to have conveyed throughout this report, you are helping to change the story of epilepsy in Ireland.

While we can't mention everyone individually, a few memorable efforts from the year include:

- The Kinsale community who came together for the Tom Clancy Jnr Memorial Golf Classic, organised by Donal Crosbie of the Bulman Bar. The event raised €5,002.
- Ciara Corcoran and her family, who held a soccer tournament in August, raising €5,622 in memory of her sister Kate.
- The family, friends, and clubmates of David O'Connell, who held a memorial cycle in June after a 6-week couch-to-50km program. The event raised €8,500, with proceeds shared equally between Epilepsy Ireland and Diabetes Ireland.
- The Glennon family, including Andrea, Sophie, Sharon and little Sophia, who once again made the trip to Dublin for the VHI Women's Mini Marathon, raising €5,800 through their ever-enthusiastic participation.
- Darcy Ryan, who took on the Monte Cristo Open Swim in Marseille in June, raising €1,470 in gratitude for the support her family received from EI.
- Louise Daly, who marked being 10 years seizure-free by taking to the skies for a charity skydive, raising €2,300 and sharing her story to inspire others.

- Ian Mentiply, who cycled over 300 miles from the North Pole to the South Pole (the pubs in Donegal and Kerry!) in memory of his brother-in-law Joe Griffin, raising €3,589 in a heartfelt tribute.
- Gavin Moran, a 16-year-old from Roscommon living with epilepsy, who led a tractor run in 2024 that raised €4,470. Inspired by Gavin's efforts, his school held a purple non-uniform day, bringing the total raised to €5,120.
- Rebecca Reid, another inspirational teenager, who spearheaded a series of community events for International Epilepsy Day, raising over €5,000
- Eoghan Meganntey from Co. Donegal, who ran the Amsterdam Marathon for Epilepsy Ireland and raised €1,650.
- Sinead Wheeler, who ran the Paris Marathon in recognition of her mum Carol, raising a fantastic €4,265 in her honour.

Capacity and Governance

Strategic Aim 6:
Demonstrate highest standards of governance & ensure structures are in place to meet objectives.

6.1 Demonstrate the highest standards of governance, financial management and quality.

The Board is committed to upholding the highest standards of corporate governance, recognising that this is a key enabler in delivering the organisation's mission and in maintaining the trust and confidence of members, service users, volunteers, funders, and donors.

Epilepsy Ireland has held the Charities Institute Ireland 'Triple Lock' best-practice standard since 2017. Maintaining this Triple Lock demonstrates that we:

- Have fully implemented the Charities Regulator's Charities Governance Code.
- Remain compliant with the Guidelines for Charitable Organisations on Fundraising from the Public.
- Prepare our annual financial statements in line with the Charities SORP (Statement of Recommended Practice under FRS102) accounting standard.

In 2021, the Board declared the organisation's full compliance with the Governance Code. Each year, we complete the Charities Governance Code Compliance Record, which was most recently reviewed and approved by the Board in September 2024.

Since 2015, we have also maintained a non-profit-specific quality standard. From 2015 to 2021, we were accredited under the PQASSO/ Trusted Charity standard. In 2021, we achieved accreditation under the Improving Quality (IQ) system at Foundation level. IQ is a UK-based standard developed for smaller non-profit organisations, assessing governance and management across the areas of accountability, welcoming, effectiveness, and sustainability. Following a reassessment by IQ in 2024, our accreditation was successfully renewed until 2027.

The Board reviews the organisation's operational and governance policies in accordance with a structured schedule agreed in 2021. Key policies such as financial controls and procedures, risk management, and directors' interests are reviewed annually, while all policies are reviewed at least once every three years.

Activities of the Board of Directors in 2024

The Board operates in accordance with the organisation's Constitution, its governance policies and procedures, and with reference to the agreed strategic and operational plans.

Eight Board meetings were held in 2024 (2023: seven). Seven of these meetings were conducted remotely, while one was held in person. During the year, the Board:

- Monitored progress at each meeting against the 2024 operational plan and budget.
- Received departmental updates from the management team across support services, training, fundraising, and advocacy/communications.
- Reviewed and reconfirmed the organisation's full compliance with the Charities Regulator Governance Code.
- Oversaw the successful re-accreditation of the IQ quality standard at Foundation level.
- Established a new Communications and Fundraising sub-committee and reorganised sub-committee memberships.
- Recruited two new members to the Finance & Audit sub-committee.
- Reviewed and approved the organisation's risk register twice during the year and agreed actions to mitigate identified risks.
- Reviewed and approved updates to 20 operational and governance policies and procedures in line with the agreed review schedule.
- Reviewed and agreed changes and movements in the organisation's designated reserves (see Reserves & Investments section).
- Made decisions on the effective use of the organisation's deposits.
- Conducted a review of the organisation's insurance policies.
- Reviewed and approved staff salary proposals, including implementation of the WRC pay agreement for Section 39 organisations.
- Agreed on actions to enhance fundraising capacity and infrastructure, including the recruitment of a new Corporate & Trusts Fundraising Executive and commissioning an external review of the organisation's CRM needs.
- Commenced a review of Epilepsy Ireland's membership structures, including a comparison with membership models in similar organisations.
- Approved a new Communications Strategy.
- Approved the creation of the voluntary role of Epilepsy Ireland Ambassador to help the organisation reach new audiences, inspire fundraising activities, and recognise supporter contributions.
- Undertook a comprehensive, externally-led Board Effectiveness Review and implemented resulting improvement actions.
- Approved updates to the Board Development Plan.
- Approved the operational plan and budget for 2025.

6.2 Strengthen our organisational structure and capacity.

Achieving the goals in our strategic plan requires a strong focus on building capacity, both in terms of staffing and at Board and sub-committee levels.
Developing our staffing structure, as outlined in the strategic plan, depends on securing sustainable income streams, a challenge in recent years. Nonetheless, 2024 saw several important developments.

In April, we recruited a new Youth Resource Officer (see Section 1.2 above), a role funded through a two-year grant from Angelini Pharma. In October, we welcomed a new Communications and Research Executive, a position approved by the Board in December 2023 and funded via the Strategic Plan Implementation designated reserve. Also in October, the Board approved the addition of a Corporate and Trusts Fundraising Officer to further strengthen our fundraising capacity.

In February 2025, the Board also approved the creation of a new Research Officer post to coordinate and grow Epilepsy Ireland's research activities, reflecting our strategic commitment to supporting and advancing epilepsy research in Ireland. This role will be funded for two years thanks to a generous unrestricted donation received in December 2024.

Strengthening our structure and capacity also includes maintaining an effective pay policy, key to attracting and retaining the skilled, motivated staff essential to delivering high-quality services and realising our strategic goals. A fair and transparent approach also helps ensure sector alignment, staff wellbeing and organisational stability. In 2024, Epilepsy Ireland implemented the WRC pay agreement reached between trade unions and the Government in 2023 for Section 39-funded staff. This agreement provided an 8% increase for all HSE-funded staff, supported by additional HSE funding. The Board also considered how to support non-HSE-funded staff as equitably as possible, within the bounds of financial prudence. A 4% increase was awarded to non-HSE-funded staff, with a further review scheduled for mid-2025.

Overall, 2024 was a stable year in terms of staff recruitment and retention. The services team returned to full capacity for the first time in several years by January 2025, and aside from the newly created fundraising position, there were no staff vacancies at year end. In June, we bid farewell to our longest-serving colleague, Agnes Mooney, who retired after more than 30 years of dedicated service as Community Resource Officer for the North-West. Agnes supported thousands of people with epilepsy across Donegal, Sligo, Leitrim and beyond, and we wish her every happiness in her well-earned retirement.

There were no new Board appointments during 2024. In December, Mary Fitzsimons stepped down from the Board after over six years of dedicated voluntary service. The Board expresses sincere thanks to Mary for her valuable insights, drawn from a distinguished career in health services and research, and we wish her all the best in retirement.

To ensure continuity and maintain a vibrant, skilled and representative Board, succession planning efforts were undertaken in anticipation of several directors reaching their term limits in 2025. Expressions of interest in joining the Board were invited from members, and by year end, several prospective candidates had been interviewed by the Governance & Nominations sub-committee.

As part of a review of sub-committee structures, the Board agreed to establish a new Communications and Fundraising sub-committee. This group now advises and supports the Board in the areas of income generation, communications, awareness-raising and advocacy. Membership across sub-committees was also reorganised, and two new non-director members joined the Finance & Audit sub-committee.

An externally-led Board effectiveness review was also carried out during the year, which confirmed strong overall performance while identifying a small number of areas for enhancement. By year end, most of the recommended actions had been implemented, with the remaining improvements scheduled for early 2025.

6.3 Invest in our technology needs.

This strategic goal came into sharper focus in 2024, and is acknowledged as a key enabler of the organisation's plans to build capacity and deliver on our strategic goals elsewhere in our strategic plan.

In October, the Board approved the commencement of a full CRM (Customer Relationship Management) scoping project, to be completed by mid-2025. This project will include an external assessment of the systems and tools currently in place across all departments, with the objective of evaluating how these systems can be further developed and integrated. The aim is to more effectively manage relationships with supporters, service users and stakeholders; improve data quality, communication, processes and workflow; reduce administrative burden; and support better decision-making. Staff across all departments will be consulted as part of the CRM review to ensure that any future system enhancements are fit-for-purpose and tailored to operational needs.

Additional developments during the year included a review of our IT support providers and the introduction of a range of enhanced cyber-security measures, alongside staff training to reinforce good practice in this area.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Brainwave the Irish Epilepsy Association CLG, trading as Epilepsy Ireland is a registered charity and hence the report and results are presented in a form which complies both with the requirements of the Companies Act 2014, and also with the Statement of Recommended Practice applicable to charities preparing their financial statements in accordance with the Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) - (Charities SORP (FRS102)).

Legal Status

The Company was incorporated on 16 September 1980 under the Companies Acts, was established under a Memorandum of Association which established its objects and powers and is governed under its Articles of Association. It is a Company Limited by Guarantee and does not have a share capital. Accordingly, neither the Directors nor the Secretary have shares or any other financial interests in the company. The objects of the Company are charitable in nature, and it has established charitable status (CHY NO. 6170) and is registered with the Charities Regulatory Authority (Registration No. 20010553).

Board of Directors

The Board of Directors of Epilepsy Ireland is responsible for setting the organisation's strategic direction and ensuring that it is governed effectively, transparently, and responsibly.

As of 31 December 2024, the Board consists of 13 volunteer members, drawn from a diverse range of backgrounds, skills, and experiences. In recent years, the Board has placed particular emphasis on achieving a balanced composition in terms of expertise, lived experience of epilepsy, and demographic representation—across factors such as age, gender, geography, and ethnicity.

Progress has been made in several areas, including improvements in age, gender, and skills diversity. However, the Board acknowledges that further work is required to strengthen ethnic diversity and to broaden regional representation.

Of the current Board members, eight have a direct personal connection to epilepsy (either living with the condition themselves or as close family members), two are healthcare professionals, and three contribute specialist knowledge and expertise essential to the Board's governance responsibilities.

Operations of the Board

The Board governs the organisation in accordance with its Constitution and an agreed governance framework. This framework includes clearly defined role specifications for Board members and officers; terms of reference for all sub-committees; a schedule of matters reserved for Board decision; and an agreed division of responsibilities between the Chairperson and the CEO.

The Board also operates under a suite of governance policies and procedures covering key areas such as confidentiality, conduct, and conflicts of interest.

Conflicts of interest are recognised as an occasional and natural occurrence in any Board setting. Epilepsy Ireland's Conflict of Interest Policy outlines the procedures for effectively identifying, recording, and managing such conflicts when they arise. A formal Register of Interests is maintained and reviewed annually. Additionally, potential conflicts are addressed as a standing agenda item at the beginning of each Board meeting, ensuring transparency in relation to the matters under discussion or decision.

Recruitment & appointment of directors

Epilepsy Ireland's Constitution outlines the rules governing the appointment of directors. Under these provisions, directors may ordinarily serve up to two four-year terms (in effect from the date of adoption in 2017).

The Constitution also sets out a minimum board size of five and a maximum of twenty members, with a requirement that at least 25% of the board must have a direct personal connection to epilepsy. It also details the procedures for appointing (including via co-option) and removing directors.

Oversight of board recruitment and development rests with the Governance & Nominations Sub-Committee. This group manages the recruitment process, including reviewing applications, conducting interviews, vetting candidates, and making appointment recommendations to the full board.

Recruitment strategies in recent years have included open calls to Epilepsy Ireland members, outreach to existing volunteers, and engagement with Boardmatch Ireland to source candidates with specific skills.

A structured induction process is in place for all new directors. Each new appointee receives a comprehensive information pack covering the organisation's operations, finances, governance structures, key policies and procedures, and recent board documentation. This is followed by one or more induction meetings with the CEO to ensure the new director is fully briefed ahead of their first board meeting.

Board Evaluation and Training

The Board of Directors is committed to ensuring continuous improvement in governance and effectiveness. Regular evaluations are conducted to assess the Board's performance and overall functioning. These evaluations help identify strengths, areas for development, and opportunities for enhanced collaboration. In addition, ongoing training and development opportunities are provided to Board members, including opportunities for individual learning and full-board development sessions. An external board effectiveness review was undertaken in 2024, yielding a very positive overall result, with a small number of minor improvements that have either been implemented or are in the process of being addressed.

Board composition.

As at 31st December 2024, the Epilepsy Ireland board members were:

Cathy Grieve (Chairperson)
Cathy was diagnosed with epilepsy in 2008. She joined the Board of Directors in 2014 and was elected as Secretary in 2016. Cathy was elected as Chairperson in December 2019 and again in 2022. Her background is in journalism and having spent 19 years as a producer and news editor with BBC News, she set up her own media production company in 2009. She has also worked as a freelance producer and as a Visiting Lecturer at City University of London.

Clare O'Dea (Company Secretary)
Clare joined the Epilepsy Ireland Board in 2017 after her son was diagnosed with a rare form of epilepsy. She brings extensive experience in corporate strategy, finance, investments, marketing, and fundraising. She holds an MBA from UCD Smurfit Graduate Business School, a Higher Diploma in Psychology from UCD, and a Diploma in Corporate Governance from the Corporate Governance Institute.

Paul Kehoe (Hon. Treasurer)
Paul joined the Epilepsy Ireland Finance & Audit sub-committee in 2017 and was elected to the Board in 2018. He currently serves as Treasurer. He is an experienced accounting and finance professional who has worked for over 40 years in the Financial Services sector including many years at AIB Global Treasury. A close family member lives with epilepsy.

Helen Behan
Helen brings a wide range of knowledge and expertise from her work in the non-profit sector, especially in governance and human resources. Her qualifications include a B.A in Social Science, a Postgraduate Diploma in Career Guidance & Development and a Diploma in Professional Human Resource Practice. She was diagnosed with Epilepsy in 2015 and joined the Board in 2021.

Aaron Chalke
Aaron is the founder and Managing Director of Foe, a film production and advertising creative studio. A DCU graduate in Multimedia, he also holds a Postgraduate Diploma in Advanced Producing for Film and TV from TUD. He has worked in the marketing and advertising sector since 2010, developing a number of award-winning campaigns with a range of international and domestic brands. Aaron joined the board in 2023.

Mark Curran
Mark joined the Board of Directors in 2023. He is a practising barrister and accredited mediator engaged in civil litigation with a particular focus on financial services & pensions law, regulatory law, judicial review, personal injuries law and employment law. Mark is a member of the Bar of Ireland and the New York State Bar and holds degrees from University College Dublin and the University of Cambridge.

Paul Fahey
Paul is a Chartered Director and member of the Institute of Directors Ireland. He is a Director of Glenough Consulting Limited which provides consultancy services to the health sector. Paul is a pharmacist who previously owned and operated a pharmacy business for over 25 years. He served as the President of the Pharmaceutical Society of Ireland from 2011-2013, and is actively involved in the International Pharmaceutical Federation (FIP).

Ambrose Kealy
Ambrose joined the board of Epilepsy Ireland in 2018. An accountant and qualified compliance professional, he is retired from the role of Chief Compliance Officer with VHI Group. He holds

professional memberships of the Institute of Directors, CIMA and the Association of Compliance officers. He is also the current Chairperson of Camphill Communities of Ireland.

Anne Kilroy
Anne joined the Board in 2021. She has a keen interest in management and living with the condition as her daughter was diagnosed with epilepsy in 2017. Her professional background is in science and she has a Master's degree in Microbial Genetics and a Ph.D. in Environmental Science. She has worked in the pharmaceutical industry both in Ireland and the USA and as a consultant in an Engineering Company.

Prof Mary King
Prof. King is a retired Consultant Paediatric Neurologist from Children's Health Ireland (CHI) at Temple St., Rotunda Hospital and Beaumont Hospital. She is a Professor in Paediatrics at University College Dublin, School of Medicine & Medical Science and has many publications in the field of Paediatric Neurology including "A Handbook of Neurological Investigations in Children". Prof. King has collaborated in several genomic projects which have led to definite diagnoses, genetic counselling and personalised treatments for many Irish families affected by epilepsy.

Anne Maguire
Anne joined the board of Epilepsy Ireland in 2023 having been diagnosed with epilepsy in 2021. She holds an MSc in Pharmaceutical Medicine, a BSc in Pharmacology and is a member of the Project Management Institute. Working in the pharmaceutical industry, focused on clinical trials, Anne has a keen interest in the research and development of medicines.

Nicola Nagle
Nicola joined the Board of Directors in 2023. She has a BSc in Accounting from UCC and is a member of the Institute of Chartered Accountants in Ireland. She is a Director in KPMG's technical accounting department with over 13 years' experience working with listed companies, private Irish family-owned business as was all not-for-profit organisations. She brings invaluable experience to the charity in financial reporting, legal and corporate governance requirements.

Nicola Saarsteiner
Nicola joined the Board of Directors in 2023. She was diagnosed with epilepsy in 2003 and subsequently volunteered for Epilepsy Ireland as a media volunteer, speaking at a number of conferences and events. She became a barrister in 2012 and practices in a number of areas in civil litigation, including personal injury, professional negligence and employment law.

Board Meeting attendance 2024

	Feb	Mar	Apr	May	July	Sept	Oct	Dec	Total
Cathy Grieve	Y	Y	Y	Y	Y	Y	Y	N	7/8
Clare O'Dea	Y	Y	N	N	Y	N	Y	Y	5/8
Paul Kehoe	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Helen Behan	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Aaron Chalke	Y	N	Y	Y	Y	Y	Y	Y	7/8
Mark Curran	Y	Y	Y	N	Y	Y	N	Y	6/8
Paul Fahey	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Mary Fitzsimons	Y	N	Y	Y	N	N	N	Y	4/8
Ambrose Kealy	Y	N	Y	Y	Y	Y	N	Y	6/8
Anne Kilroy	Y	N	Y	Y	N	Y	Y	Y	6/8
Mary King	Y	Y	N	N	Y	Y	Y	Y	6/8
Anne Maguire	Y	Y	Y	Y	N	Y	Y	N	6/8
Nicola Nagle	N	Y	Y	N	Y	N	N	N	3/8
Nicola Saarsteiner	Y	Y	Y	Y	Y	N	Y	Y	7/8

Y	Present
N	Apologies

Role and activities of sub-committees

The Board has established a number of sub-committees to consider specific matters and make recommendations to the Board in line with their terms of reference. Following changes in Board composition during 2023, membership of the sub-committees was reviewed and updated in early 2024. As part of this process, the Business Development & Sustainability sub-committee was dissolved, and a new Communications & Fundraising sub-committee was established. The current sub-committees are:

Finance & Audit sub-committee:
This sub-committee assists and advises the Board on matters related to finance, risk, investments and reserves, general business activities, and strategic direction. It includes both Board members and independent external experts. In 2024, the committee met seven times and made recommendations on annual budgeting, risk management, financial controls, pay policy, fundraising strategy, and the use of reserves and deposits. It also received regular updates on fundraising and funding activities and oversaw the annual audit process. Two new external members, Caoimhe Neary and Liam Woulfe, were appointed in early 2024.

Governance & Nominations sub-committee:
This sub-committee provides support to the Board on all governance matters, including Board composition, development, and recruitment. It met three times in 2024, focusing on Board and sub-committee recruitment, implementing recommendations from the 2024 external Board effectiveness review, recommending a Board development plan, reviewing Governance Code compliance, internal policy updates, and reviewing the organisation's Constitution.

Quality & Safety sub-committee:
This sub-committee oversees quality, safety, and risk management across the organisation's services. It met three times in 2024 and addressed issues such as the organisational risk register and risk management policy, health and safety (including seizure management), complaints, and oversight of the *Improving Quality (IQ)* accreditation process.

Remuneration sub-committee:
Comprising the Chairperson, Company Secretary, and Treasurer, this sub-committee is responsible for setting the CEO's objectives, conducting the CEO's annual appraisal, and reporting to the Board on performance. It met once in 2024 to carry out the CEO appraisal.

Communications & Fundraising sub-committee:
Established in 2024, this new sub-committee replaces the former Business Development & Sustainability sub-committee. Its purpose is to provide strategic advice and support operational goals in the areas of external communications (including awareness and advocacy) and income generation. It met three times in 2024, focusing on reviewing and recommending the communications strategy to the Board, developing new advocacy priorities, and reviewing the 2024–2026 Fundraising Plan ahead of full Board discussion.

Research sub-committee:
This sub-committee was established in 2023 to provide expert advice to the Board on matters relating to epilepsy research and furthering our strategic objective of funding and collaborating with research partners to increase knowledge of epilepsy, its causes, effects and management. The sub-committee did not meet in 2024 as there were no active research funding calls during the year.

Role of Management

The Board delegates operational leadership, management and strategic implementation to the chief executive who oversees the wider management team and staff and reports to the Board regularly on all services and activities, as well as administrative and financial matters.

The senior management team consists of the Director of Services, Finance Manager, Training & Quality Manager, Advocacy & Communications Manager and Fundraising & Development Manager.

FINANCIAL REVIEW

Results for the Financial Year	**2024** **€**	2023 €
Net income for the financial year	**186,597**	146,226

Epilepsy Ireland's principal sources of funding are described above under Strategic Aim 5.1.

In 2024, Epilepsy Ireland recorded a surplus of €186,597, significantly exceeding the projection outlined in the 2024 budget. This marks the organisation's second consecutive year of surplus (2023: €146,226).

The positive outcome was primarily driven by unexpected legacy income of €157,500 and a significant donation of €90,000 received at year-end. In addition, other fundraising streams, including donations, churchgate collections, and income from marathons and challenge events, performed above expectations. However, some fundraising activities underperformed, particularly events, corporate fundraising, and social media campaigns, the latter of which was affected by the discontinuation of Facebook fundraising in June.

These factors, combined with increased income from training and HSE funding of €72,719, provided in 2024 to meet obligations under the Section 39 Pay Agreement negotiated by trade unions and the Government, meant that overall income rose to €1.969 million (2023: €1.868 million).

While overall expenditure also increased slightly to €1.783 million (2023: €1.722 million), it also remained below the forecasted level. Staff costs increased from €1.021m in 2023 to €1.167m in 2024, reflecting both the implementation of the WRC pay agreement and an increase of one in the average number of employees throughout the year. However, staff costs were lower than expected due to vacancies and recruitment delays. Some planned project and fundraising expenditures were also not incurred during the year. Management continues to maintain a strong focus on cost control across all areas of the organisation's operations.

Reserves and Investments

Total funds held at the end of 2024 are €1,796,321 (2023: €1,609,724). This comprises restricted funds of €118,938, designated funds of €580,218 and an unrestricted operational reserve of €1,097,165.

Restricted funds include €14,875 in HSE-related funds (including National Lottery funding) and €82,576 raised by the Young family between 2021 and 2024, which will support the continued expansion of the pilot 'Aids & Appliances' scheme launched in 2024 (described in Section 2.1 of the Achievements and Performance section). The restricted amount also includes funding of €8,087 (2023: €9,327) from Edwards Lifesciences (provided in 2022 for the same scheme), along with several smaller grants earmarked for specific purposes in future periods.

Designated reserves are set aside by the Board for specific strategic purposes, including undertaking epilepsy awareness campaigns; providing funding for current and future research projects; and for upgrading/relocating the charity's head office in Crumlin. The Board also maintains a reserve to facilitate implementation of the organisation's Strategic Plans.

In 2024, the Research reserve was reduced by €53,854 to meet the cost of research grants provided in the year. In its annual review of designated reserves, the Board agreed to replenish this reserve to €150,000 to meet the cost of future anticipated investments in medical research. The Awareness reserve was reduced by €29,512, representing costs associated with the 2024 International Epilepsy Day campaign. The Board also decided to replenish this reserve to €100,000 to provide for future annual campaigns. The Strategic Plan implementation reserve was reduced by €9,782, representing the cost of a new staff role approved by the board in December 2023.

The Board also approved the creation of a new designated reserve of €90,000 to support the employment of a new Research Officer staff position from 2025, utilising an unrestricted donation received in December 2024. As a result of these movements, total designated funds at year-end stood at €580,218 (2023: €500,000).

At the end of 2024, unrestricted operational reserves were €1,097,165 (2023: €984,617). Per our reserves policy, the purpose of these reserves is to protect the financial stability of the organisation in order to deliver on our mission and strategic objectives and to maintain ongoing operations that support the mission and objectives. The policy requires maintaining a minimum of six months' operational expenditure in reserve to ensure continued financial security and to provide for contingencies. It also stipulates that the combined total of the unrestricted operational reserve and designated funds is at least €1 million. The reserves position at the end of 2024 complies with these requirements.

The organisation's investment policy (updated in 2024) details our approach to investing/ depositing available funds.

The policy details targets for liquidity, short term deposits (≤ 3 years) and medium-term deposits (3-5 years).

Liquid funds consist of current accounts held at Bank of Ireland and AIB, intended to meet day to day expenditure.

Short-term deposits include term deposit accounts held with Bank of Ireland, Permanent TSB, and in State Savings Bonds. These deposits prioritise capital protection while also ensuring readily accessible liquidity.

Medium-term investments are intended to preserve the purchasing power of the organisation's reserves over time, while adhering to a low-risk investment strategy. A cap is applied to such investments, limited to the lower of €250,000 or 20% of Epilepsy Ireland's total balance sheet funds at the time of investment.

The table below summarises the current investment structure and allocations as of 31st December 2024:

	Liquidity	**Short Term Deposits**	**Medium Term Reserves**
Objective	Access	Capital Protection	Capital Growth (negate inflationary pressures)
Target Funds	>€250,000	>€1,000,000	<€250,000 (<20%)
Actual Funds	€ 658,447	€ 1,114,983	€0

Risks and uncertainties

The Board has approved a risk management policy and maintains a comprehensive risk register that outlines all organisational risks, corresponding mitigation measures, and actions required to minimise them. The register is reviewed twice annually by the Board, as well as by the Finance & Audit and Quality & Safety sub-committees.

Risks are categorised across a number of areas, including human resources, information technology, fundraising, finance, services, governance, communications/advocacy, strategy, and other risks. Each risk is assessed based on its likelihood and potential impact and is rated as high, medium, or low on both an inherent and residual basis.
Based on the most recent review of the risk register by the Board (February 2025), the most significant risks currently facing the organisation are summarised below, along with a summary of mitigation measures:

Insufficient capacity to meet: changes in service demand; compliance requirements; stakeholder expectations; or strategic plan aims.
Actions: Seek out funds to develop volunteer programme envisaged in strategic plan; recruit for new role of Research Officer in 2025 and fill vacancies that arise; facilitate the service user consultation group and undertake service user satisfaction/ feedback surveys; monitor capacity challenges through reports to board and planning activities; identify funding opportunities to enable further expansion of staffing resources in target areas.

Drop in Fundraising Income/ Poorly performing fundraising activities.
Actions: Revisit Fundraising Plan 2024-2026 in mid-2025 and progress further developments/ investments agreed by Board by year end; recruit for new role of Corporate & Trusts Fundraising Officer; review organisation's CRM needs and implement development actions needed; close monitoring of fundraising activities and data including those which may be under-performing; implement actions in 2025 operational plan.

Inadequate HSE funding; overdependence on HSE income
Actions: Board to revisit implementation of 2024-2026 fundraising plan in mid-2025; meet income generation targets in 2025 budget/ operational plan; ongoing advocacy and engagement with sectoral efforts to increase Section 39 funding, outside of WRC pay agreement increases; monitor and apply for new funding opportunities including via HSE business cases; continue to review and monitor reserves.

Relationship with key funders
The risk rating was elevated to reflect uncertainty on how Section 39 organisations may be funded in future, as well as changes being made by HSE in 2025 regarding service level agreements and structural changes to HSE's regional governance. The rating also reflects the growing volume and complexity of reporting and compliance obligations associated with various funding arrangements in recent years. We will continue to engage with HSE and sectoral representative bodies to manage and navigate these developments.

External Factors (i.e. public health crises, economic and political environment)
Actions: Ensure Business Continuity Plan and Crisis Communications plans are up to date; develop environmental & social policy; ensure reserves and deposits are regularly monitored and utilised as per the reserves policy and investment policy.

Financial risks continue to represent the most significant area of concern. The Board acknowledges Epilepsy Ireland's dependence on HSE Section 39 funding for the delivery of core services and recognises the need to increase unrestricted income in the medium-to-long term. Steps taken in 2024 to build fundraising capacity will be followed up in mid-2025 by the Board. The Board is confident that the assumptions underpinning the 2025 budget are sound and believes that the organisation is well-positioned to respond to any emerging financial challenges through appropriate use of reserves or cost management measures.

Going Concern

Taking into account the analysis of financial performance, the current funding and fundraising environment, identified risks and uncertainties, future forecasts and projections, and the reserves held by the organisation, the Board has a reasonable expectation that there are adequate resources to continue operating within existing cash flows and reserves for the foreseeable future. As such, the Board continues to adopt the going concern basis of accounting in preparing the annual financial statements.
Accordingly, these financial statements do not include any adjustments to the carrying amounts or classification of assets and liabilities that may arise should the company be unable to continue as a going concern. Further information is provided in Note 3 to the financial statements.

Internal controls

The board has established procedures to address the board's responsibility to maintain, review and report on internal financial controls and procedures, including in relation to the receipt, recording and control of all income received. These controls are reviewed and updated annually, based on the recommendation of the Finance & Audit sub-committee. The most recent review of the organisation's Financial Controls and Procedures took place in October 2024.

The Finance and Audit sub-committee reports directly to the board through the Treasurer on financial controls and risks. A detailed annual budget is prepared, reviewed and approved annually by the sub-committee and board. The budgeted income and expenditure are monitored throughout the year to ensure alignment with plans and with financial resources available. Forecasts are updated ahead of sub-committee and board meetings.

FUTURE PLANS

Epilepsy Ireland remains committed to delivering for the epilepsy community across Ireland through our support services, advocacy, training, awareness raising activities and research. Our work in 2024 was strengthened by the dedication of our staff and volunteers, the support of our donors and funders, and the guidance of our Board.

While challenges remain, particularly in the areas of funding and capacity, the organisation is in a strong position to meet its strategic goals and respond to emerging needs. We are proud of the progress made in the past year and are focused on building on this momentum in 2025 and beyond, always working towards our vision of a society where no person's life is limited by epilepsy.

As outlined in the Objectives & Activities section, the Board approved a five-year Strategic Plan in 2022 to guide us through to 2026 on working towards that vision.

In July 2024, the Board conducted a mid-point review of the plan and progress achieved to date. This provided an important opportunity to assess the continued relevance and feasibility of our objectives, to consider changes in the external environment, and to make minor adjustments to the plan where necessary.

Our plans for the remaining two years (to end-2026), as set out in the original Strategic Plan and updated following the 2024 review, can be summarised as follows for each of the six strategic aims:

Empowering people with epilepsy through support and education.

We will continue to provide information, advice and support to people living with epilepsy, their families and carers. We will work to empower people in the self-management of their condition through one-to-one and group-based work, while also further developing our online service delivery. We will work to reduce or remove potential barriers for people with epilepsy in education and employment by working with and upskilling schools and employers. We will develop information resources appropriate to the needs of those living with epilepsy and professionals. We will seek to identify gaps in service delivery, including for those with specific or complex needs and work to develop supports to meet identified needs. We will also expand the provision of epilepsy aids & appliances and put new links and referral pathways in place with the medical community.

Centring people with epilepsy and their families in the work of Epilepsy Ireland.

Recognising that the success of the organisation is dependent on an active and engaged base of members and volunteers, we will increase the number of volunteers engaged with the organisation and harness the expertise of those living with epilepsy to support the delivery of work across the organisation. We will increase opportunities for people with lived experience to contribute to our work and we will develop mechanisms to consult with and seek feedback from our membership about our services and wider activities. We will also review our membership model; assess if and how greater value can be added and ultimately increase our membership base.

Working collaboratively to improve the care of people with epilepsy and knowledge of the condition.

We will work with relevant stakeholders to improve access to care and and promote a greater focus on community-based care. We will work with the medical community to provide epilepsy training opportunities for health professionals and continue to deliver and grow our own training programmes. We will develop a research strategy to guide our investments in epilepsy research, expand our ability to collaborate as research partners and promote the increased involvement of people with epilepsy in epilepsy research. Finally, we will work with the medical community to promote improved knowledge and understanding of SUDEP and advance strategies to reduce the risk and incidence of epilepsy deaths.

Transforming perceptions of epilepsy and public policy relevant to the condition

Improving public understanding, knowledge and visibility of epilepsy remains a key priority. We will continue to use targeted awareness campaigns such as International Epilepsy Day, Brain Awareness Week and others to reduce stigma and discrimination and improve public awareness of and attitudes to epilepsy. We will design and implement advocacy campaigns on issues that reflect the needs of people with epilepsy to create positive change. We will also expand our social media reach and engagement, raise the profile of the organisation and ensure that all public communications are centred on a diverse range of personal experiences of epilepsy.

Increasing and diversifying our income

Implementing our strategic objectives requires successful income generation strategies. We will increase and diversify our fundraising streams including through corporate partnerships, regular and digital giving, and by embracing new techniques and technologies. We will review and where possible grow existing fundraising activities and aim to develop Purple Day® into a flagship annual fundraising event. We will also expand earned income activities e.g. our training services, and work with state funders, particularly the HSE, to secure increases in grant funding for the delivery and enhancement of our services.

Demonstrating the highest standards of governance and ensure the structures are in place to meet objectives.

Demonstrating the highest standards of governance, financial management and quality is vital to preserving our reputation and the confidence of our service users, members, funders, donors and other stakeholders. We will maintain compliance with the Charities Governance Code and preserve our Triple Lock Standard, as well as maintaining our quality assurance framework. We will ensure we are governed by a diverse, skilled Board and we will work to secure funding for additional staff posts needed to deliver on our strategic objectives. We will invest in the technology needed to effectively and efficiently deliver on our goals in service delivery, training, communications, fundraising and administration.

Operational Plan for 2025

Each year, the Board of Epilepsy Ireland approves an Operational Plan and budget, aligned with the Strategic Plan, to outline the organisation's priorities for the year ahead. Progress against this plan is closely monitored and reviewed at each Board meeting.
Key actions set out in the 2025 Operational Plan include:

- Deliver high-quality, one-to-one support services, with a target of at least 7,500 individual contacts and 7,500 group contacts.
- Reconfigure the STEPS epilepsy self-management programme.
- Complete the development of a resource pack on epilepsy for healthcare professionals.
- Develop and grow the Young Epilepsy Programme.
- Grow the seizure detection device reimbursement scheme, including expansion to new referral sites and support for additional devices.

POLITICAL DONATIONS

The company did not made any political donations in the financial year (2023 - €nil).

POST BALANCE SHEET EVENTS

There have been no significant events affecting the company since the financial year end.

ACCOUNTING RECORDS

The measures that the directors have taken to secure compliance with the requirements of sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records, are the employment of appropriately qualified accounting personnel and the maintenance of computerised accounting systems. The company's accounting records are maintained at the company's registered office at 249 Crumlin Road, Dublin 12.

DISCLOSURE OF INFORMATION TO AUDITORS

In the case of each of the persons who are directors at the time the directors' report and financial statements are approved:

A) So far as the director is aware, there is no relevant audit information of which the company's auditors are unaware; and

B) Each director has taken all steps that ought to have been taken by the director in order to make himself/herself aware of any relevant audit information and to establish that the company's auditors are aware of that information.

AUDITORS

The auditors, Forvis Mazars, Chartered Accountants and Statutory Audit Firm, continue in office in accordance with Section 383(2) of the Companies Act 2014.

Approved by the Board and signed on its behalf by:

Paul Fahey
Director

Paul Kehoe
Director

Date: 20th May 2025

DIRECTORS' RESPONSIBILITIES STATEMENT

The directors are responsible for preparing the directors' report and the financial statements in accordance with Irish law and regulations.

Irish company law requires the directors to prepare financial statements for each financial year. Under that law, the directors have elected to prepare the financial statements in accordance with FRS 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* issued by the Financial Reporting Council and Statement of Recommended Practice (Charities SORP (FRS 102)), issued by the Charity Commission for England and Wales, the Charity Commission for Northern Ireland and the Office of the Scottish Charity Regulator.

Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the company as at the financial year end date and of the surplus or deficit of the company for the financial year and otherwise comply with the Companies Act 2014.

In preparing those financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with the applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets, liabilities, financial position and surplus or deficit of the company to be determined with reasonable accuracy, enable them to ensure that the financial statements and directors' report comply with the Companies Act 2014 and enable the financial statements to be audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The directors are responsible for the maintenance and integrity of the corporate and financial information included on the company's website. Legislation in Ireland governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Approved by the Board and signed on its behalf by:

Paul Fahy

Paul Fahey
Director

Paul Kehoe

Paul Kehoe
Director

Date: 20th May 2025

Independent auditor's report to the members of BRAINWAVE – THE IRISH EPILEPSY ASSOCIATION

Report on the audit of the financial statements

Opinion

We have audited the financial statements of Brainwave – The Irish Epilepsy Association ('the Charity'), for the year ended 31 December 2024, which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows, and notes to the Company financial statements, including the summary of significant accounting policies set out in note 3. The financial reporting framework that has been applied in their preparation is Irish Law and FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland issued in the United Kingdom by the Financial Reporting Council (FRS 102).

In our opinion, the accompanying financial statements:

- give a true and fair view of the assets, liabilities and financial position of the Charity as at 31 December 2024, and of its surplus for the year then ended;
- have been properly prepared in accordance with FRS 102; and
- have been properly prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's Responsibilities for the Audit of the Financial Statements* section of our report.

We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of financial statements in Ireland, including the Ethical Standard for Auditors (Ireland) issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), 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 directors' 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 Charity's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

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

Other information

The directors are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

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 there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2014

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

- the information given in the directors' report for the financial year for which the financial statements are prepared is consistent with the financial statements;
- the directors' report has been prepared in accordance with applicable legal requirements;
- the accounting records of the Charity were sufficient to permit the financial statements to be readily and properly audited; and
- the financial statements are in agreement with the accounting records.

We have obtained all the information and explanations which, to the best of our knowledge and belief, are necessary for the purposes of our audit.

Matters on which we are required to report by exception

Based on the knowledge and understanding of the Charity and its environment obtained in the course of the audit, we have not identified any material misstatements in the directors' report.

The Companies Act 2014 requires us to report to you if, in our opinion, the requirements of any of Sections 305 to 312 of the Act, which relate to disclosures of directors' remuneration and transactions are not complied with by the Charity. We have nothing to report in this regard.

Respective responsibilities

Responsibilities of directors for the financial statements

As explained more fully in the directors' responsibilities statement out on page 36, the directors are responsible for the preparation of the financial statements in accordance with the applicable financial reporting framework that give a true and fair view, and for such internal control as management determines 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 directors are responsible for assessing the Charity'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 management either intends to liquidate the Charity or to cease operations, or has 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 auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Irish Auditing and Accounting Supervisory Authority's website at: http://www.iaasa.ie/getmedia/b2389013-1cf6-458b-9b8f-a98202dc9c3a/Description_of_auditors_responsibilities_for_audit.pdf. This description forms part of our auditor's report.

The purpose of our audit work and to whom we owe our responsibilities

Our report is made solely to the Charity's members, as a body, in accordance with Section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the Charity'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 Charity and the Charity's members, as a body, for our audit work, for this report, or for the opinions we have formed.

Aedín Morkan.

Aedín Morkan
for and on behalf of Mazars
Chartered Accountants & Statutory Audit Firm
Harcourt Centre, Block 3
Harcourt Road
Dublin 2
Date: 30 May 2025

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2024

	Note	**Restricted Funds 2024 €**	**Unrestricted Funds 2024 €**	**Total Funds 2024 €**	Restricted Funds 2023 €	Unrestricted Funds 2023 €	Total Funds 2023 €
INCOME FROM:							
Donations and Legacies	*4*	**74,381**	**544,710**	**619,091**	81,532	450,191	531,723
Charitable Activities	*5*	**917,860**	**241,532**	**1,159,392**	963,021	207,245	1,170,266
Other Trading Activities	*6*	**30,403**	**115,212**	**145,615**	38,505	100,904	139,409
Interest Income	*7*	-	**20,768**	**20,768**	-	4,271	4,271
Other Income	*8*	-	**24,872**	**24,872**	-	22,950	22,950
Total		**1,022,644**	**947,094**	**1,969,738**	1,083,058	785,561	1,868,619
EXPENDITURE ON:							
Charitable activities	*9(a)*	**1,071,091**	**404,350**	**1,475,441**	1,131,845	351,242	1,483,087
Raising funds	*10*	**16,004**	**291,696**	**307,700**	14,261	225,045	239,306
Total		**1,087,095**	**696,046**	**1,783,141**	1,146,106	576,287	1,722,393
NET (EXPENDITURE)/ INCOME	*13*	**(64,451)**	**251,048**	**186,597**	(63,048)	209,274	146,226
Taxation	*11*	-	-	-	-	-	-
Transfer between funds	*21*	**58,282**	**(58,282)**	-	101,750	(101,750)	-
Net movement in funds for financial year	*21*	**(6,169)**	**192,766**	**186,597**	38,702	107,524	146,226
Total funds brought forward	*21*	**125,107**	**1,484,617**	**1,609,724**	86,405	1,377,093	1,463,498
Total funds carried forward	*21*	**118,938**	**1,677,383**	**1,796,321**	125,107	1,484,617	1,609,724

There are no recognised gains or losses other than the income and expenditure as stated above for the two financial years.

All income and expenditure derive from continuing activities.

The notes on pages 43 to 58 form part of these financial statements.

BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND

BALANCE SHEET
AS AT 31 DECEMBER 2024

	Note	**2024** **€**	2023 €
Fixed Assets			
Tangible assets	*14*	**115,955**	122,546
Non-current Assets			
Investments maturing in more than one year	*15*	**344,559**	890,423
Current Assets			
Short-term investments	*15*	**770,424**	221,330
Debtors	*16*	**174,579**	246,867
Cash at bank and in hand	*17*	**658,447**	371,215
		1,603,450	839,412
Current Liabilities			
Creditors: Amounts falling due within one year	*18*	**(267,643)**	(242,657)
Net Current Assets		**1,335,807**	596,755
TOTAL NET ASSETS		**1,796,321**	1,609,724
FUNDS OF THE CHARITY:			
Restricted funds	*21*	**118,938**	125,107
Unrestricted funds			
- Operational Reserve	*21*	**1,097,165**	984,617
- Designated funds	*21*	**580,218**	500,000
TOTAL FUNDS		**1,796,321**	1,609,724

The notes on pages 43 to 58 form part of these financial statements.

The financial statements were approved and authorised for issue by the Board of Directors on the 20th May 2025 and signed on its behalf by:

Paul Fahey
Director

Paul Kehoe
Director

BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND

STATEMENT OF CASH FLOWS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2024

RECONCILIATION OF NET INCOME TO CASH USED IN ALL ACTIVITIES

	Note	**2024** **€**	**2023** **€**
Net income for the year		**186,597**	146,226
Adjustments for:			
Depreciation	14	**13,601**	29,804
Decrease/(increase) in debtors		**72,288**	(97,174)
Increase in creditors		**24,985**	54,992
Net cash flows from operating activities		**297,471**	133,848
Cash flows from investing activities			
Purchase of tangible assets	14	**(7,010)**	(12,685)
Interest gains from short-term investments		**(2,029)**	-
Proceeds from matured short-term investments		**120,000**	-
Purchase of short-term investments		**(121,200)**	(751,753)
Cash used in investing activities		**(10,239)**	(764,438)
Change in cash at bank and in hand during the year		**287,232**	**(630,590)**
Cash at bank or in hand at the beginning of the year		**371,215**	**1,001,805**
Cash and cash equivalents at end of year		**658,447**	**371,215**
Reconciliation to cash at bank and in hand:			
Cash at bank and in hand		**658,447**	**371,215**

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1. GENERAL INFORMATION

Brainwave-The Irish Epilepsy Association T/A Epilepsy Ireland is a company incorporated in Ireland under the Companies Act 2014. The address of the registered office is 249 Crumlin Road, Dublin 12. The nature of the company's operations and its principal activities are set out in the Directors' Report on pages 3 to 35. In accordance with Section 1180(8) of the Companies Act, 2014, the company is exempt from including the word "Limited" in its name. The company is limited by guarantee and has no share capital. Accordingly, neither the Directors nor the Secretary have shares or any other financial interests in the company. The company is a public benefit entity. In prior years companies not trading for gain for the members were not within the scope of company law requirements with regard to formats and content of financial statements which applied to for profit companies thus permitting the adoption of a format appropriate to a charity. Accordingly, the company adopted and reported its performance in accordance with the format provided for in the Charities SORP and in particular reports its performance for the financial year in the format of the SORP's Statement of Financial Activities (SOFA).

The principal activities of the company are disclosed on page 3 of the Directors' report.

2. STATEMENT OF COMPLIANCE

The financial statements have been prepared in accordance with FRS102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" (FRS102).

3. ACCOUNTING POLICIES

The following accounting policies are applied consistently in dealing with items which are considered material in relation to the company's financial statements:

3.1 Basis of Preparation

The financial statements have been prepared under the historical cost convention, modified to include certain items at fair value, and in accordance with the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" in accordance with the Financial Reporting Standard applicable in the UK (which has been recognised as best practice for financial reporting by charities in Ireland) and Republic of Ireland (FRS 102), issued by the Financial Reporting Council, and the Companies Act 2014.

The functional currency of Brainwave-The Irish Epilepsy Association T/A Epilepsy Ireland is considered to be euro because that is the currency of the primary economic environment in which the company operates.

3.2 Income

Income is recognised when the Company has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably. Income is deferred where the charity is limited by specific performance related conditions that are evident in the funding agreement, where there is a specification of a time period that limits the charity's ability to recognise the income until it has performed an activity and when there are specific terms or conditions within an agreement that have not been met and are not within the control of the charity at year end.

3. ACCOUNTING POLICIES (continued)

3.2 Income (continued)

(a) Grants
Income from government and other grants, whether capital grants or revenue grants, is recognised when the Company has entitlement to the funds, any performance conditions attached have been met, it is probable that the income will be received and the amount can be measured reliably.

(b) Legacies
For legacies, entitlement is taken as the earlier of the date on which either the Company is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Company that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the Company or the company is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

(c) Donations
Funds from public donations and other income generated through fundraising events are recorded upon receipt into our account or fundraising platforms.

As with many similar charitable organisations, independent groups from time to time organise fundraising activities. However, as amounts collected this way are outside the control of the company, they are not included in the financial statements until received by the company. Donations in kind represent goods or services provided to the charity free of charge. Where valuation can be measured with reasonable certainty, donations in kind are recognised in full as income in the year of receipt. Donations are valued at the cost to the donor or the amount normally chargeable by the donor for the goods or services provided. If such a valuation is not available, reasonable prevailing market rates are used. A matching expenditure is recognised when the goods or services are received.

(d) Training income
Training Income is recognised when the Company has entitlement to the funds once the service has been provided.

(e) Interest Income
Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Company. This is normally upon notification of the interest paid or payable by the bank.

(f) Deferred Income
Income is deferred where the charity is limited by specific performance related conditions that are evident in the funding agreement, where there is a specification of a time period that limits the charity's ability to recognise the income until it has performed an activity and when there are specific terms or conditions within an agreement that have not been met and are not within the control of the charity at year end.

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3. ACCOUNTING POLICIES (continued)

3.3 Fund Accounting

The following funds are operated by the Charity:

General Funds - Operational Reserve
General Funds represent amounts which are expendable at the discretion of the Board of Directors in furtherance of the objective of the charity which have not been designated for other purposes. Such funds may be held to finance working capital or capital expenditure.

Designated Funds
Designated funds are unrestricted funds earmarked by the Board of Directors for particular purposes.

Restricted Funds
Restricted funds represent income, which has been received and recognised in the financial statements, which is subject to specific restrictions imposed by the donors or grant making institution.

3.4 Expenditure

Expenditure is recognised when a legal or constructive obligation exists as a result of a past event, a transfer of economic benefits is required in settlement and the amount of the obligation can be reliably measured.

Charitable activities
Resources expended on charitable activities comprise all the resources applied by the Company in undertaking the work to meet its charitable objectives. This includes the direct costs of undertaking these activities and the support costs incurred to enable these activities to be undertaken. All costs of charitable activities are recognised on an accruals basis.

Fundraising activities
The cost of fundraising activities comprises costs incurred in fundraising, including the cost of promotional materials, staff costs, administration costs, governance costs and an allocation of support costs. All costs of fundraising are recognised on an accruals basis.

Allocation of support costs
Support costs are incurred on those functions that assist the work of the Company but do not directly undertake charitable activities. Support costs are analysed between cost of raising funds and expenditure on charitable activities. Where costs cannot be directly attributed, they are allocated in proportion to the benefit received.

3.5 Tangible Fixed Assets and Depreciation

Tangible Fixed assets are stated at cost less accumulated depreciation. Depreciation is calculated to write off the cost of the fixed assets over their useful lives at the following annual rates.

Premises	:	1% straight line
Fixtures and fittings	:	20% straight line
Computer and office equipment	:	33.33% straight line

3. ACCOUNTING POLICIES (continued)

The carrying values of tangible assets are reviewed annually for impairment if events or changes in circumstances indicate the carrying amount may not be recoverable.

3.6 Short-term investments

Short-term investments are included on the Balance Sheet at their fair value. Investments are classified as current assets on the Balance Sheet as they can be converted to cash within three months. The primary investment objectives are to:

- Provide a stable source of liquidity and financial support for Epilepsy Ireland so that it can achieve its mission into the future.
- Attempt to maintain the purchasing power of the reserves in real terms.
- Maintain a low risk profile by limiting investment to Fixed Income or Fixed income-like investments. All investment income is treated as unrestricted income.

3.7 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discount.

3.8 Cash at bank and in hand

Cash at bank and in hand are basic financial assets and include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts.

3.9 Creditors and Provisions

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 settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discount due.

3.10 Retirement benefits

Retirement benefits for certain employees are funded by contributions from the company and the employees. Payments are made to a pension trust which is financially separate from the company. These payments are included in expenditure in the year in which they are paid. The scheme is a defined contribution scheme.

3.11 Critical Accounting judgements and key sources of estimation uncertainty

In the application of the company's accounting policies, which are described above, the directors are required to make judgements, estimates and assumptions about the carrying amounts of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates. The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period or in the period of the revision and future periods if the revision affects both current and future periods.

3. ACCOUNTING POLICIES (continued)

Judgements and estimates are continually evaluated and are based on historical experiences and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

The estimates and assumptions that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial are discussed below.

(a) Going Concern

The directors have prepared budgets and cash flows for a period of at least twelve months from the date of the approval of the financial statements which demonstrate that there is no material uncertainty regarding the company's ability to meet its liabilities as they fall due, and to continue as a going concern. The key judgement applied in the preparation of budgets and cash flows is that considering the analysis above of financial performance pg. 28, the funding and fundraising environment, current risks and uncertainties, our current forecasts and projections, and the reserves held by the charity, the Board has a reasonable expectation that there are adequate resources to operate within its current cash flows and reserves for the foreseeable future. Therefore, the Board continues to adopt the going concern basis of accounting in preparing the annual financial statements. Accordingly, these financial statements do not include any adjustments to the carrying amount and classification of assets and liabilities that may arise if the company was unable to continue as a going concern.

(b) Establishing useful economic lives of tangible fixed assets

The company reviews annually the estimated useful lives of tangible fixed assets based on the asset's expected utilisation, market demands and future technological development. It is possible that the factors mentioned may change in the future, which could cause a change in estimated useful lives.

There were no changes in the estimated useful lives of tangible assets during 2024.

4. DONATIONS AND LEGACIES

	Restricted funds	**Unrestricted funds**	**Total 2024**	Total 2023
	€	**€**	**€**	€
Collections	-	116,847	**116,847**	111,205
Donations	57,269	263,870	**321,139**	166,906
Donations In Kind	17,112	-	**17,112**	45,437
Memberships	-	6,493	**6,493**	3,704
Legacies	-	157,500	**157,500**	204,471
	74,381	544,710	**619,091**	531,723

Income received is primarily from the Republic of Ireland.

Restricted In-Memory donations of €1,682 were received in 2024.The restricted fund balance carried forward of €82,576 (2023: €80,894), relates to total funds raised between 2021 and 2024 specifically to launch a new service to provide wearable seizure-monitoring devices to service users as detailed in note 21.

A restricted donation of €5,000 was received in 2024 from Crown Roofing and Cladding Ltd towards the provision of Training and Awareness raising activities.

In accordance with our policy on working with pharmaceutical & medical device industries, Epilepsy Ireland discloses all contributions from this sector. In 2024, we received the following contributions which are included in donations:
- Angelini Pharma; €40,587 grant to fund the Youth Resource Officer role.
- Neuraxpharm Ireland; €10,000 towards the cost of providing our training services.
- Desitin Pharma; €5,000 unrestricted educational grant.

A non-cash in-kind donation of €16,912 received from Connelly Partners is included under Restricted Donations, representing a donated service in relation to the development and promotion of a public awareness campaign. A non-cash amount of €200 is included under Donations in kind, representing a donated voucher from Dunnes in relation to the Annual Members Raffle.

5. INCOME FROM CHARITABLE ACTIVITIES

Grant Income

Grantor	**Grant Name**	**Purpose**	**Restricted funds** **€**	**Unrestricted funds** **€**	**Total 2024** **€**	Total 2023 **€**
HSE	CHO 1	Service Agreement	47,288	-	**47,288**	47,288
HSE	CHO 2	Service Agreement	3,800	-	**3,800**	3,800
HSE	CHO 3	Service Agreement	20,423	-	**20,423**	20,423
HSE	CHO 4	Service Agreement	111,603	-	**111,603**	111,603
HSE	CHO 5	Service Agreement	45,813	-	**45,813**	45,813
HSE	CHO 7	Service Agreement	483,997	-	**483,997**	483,997
HSE	CHO 7	National Lottery	5,000	-	**5,000**	3,000
HSE	CHO 8	Service Agreement	37,224	-	**37,224**	37,224
HSE	Inflation Fund	Service Agreement	-	-	**-**	29,449
HSE	WRC Funding	Service Agreement	72,719	-	**72,719**	-
Mayo Sligo Leitrim ETB	Specialised Training	Training For Success	-	-	**-**	69,431
Pobal	SSNO	Salary and assoc. costs (2 positions)	84,993	-	**84,993**	84,993
RTE Toy Show Fund	Fund	Service Delivery	-	-	**-**	26,000
			912,860	-	**912,860**	963,021
Non-Grant Income						
BM Training Programme			-	228,765	**228,765**	199,730
Other Income Generating Services				11,517	**11,517**	7,515
Other Grants			5,000	1,250	**6,250**	-
Total Non-Grant Income			5,000	241,532	**246,532**	207,245
Total Income from Charitable Activities			917,860	241,532	**1,159,392**	1,170,266

Epilepsy Ireland is compliant with relevant Circulars, including Circular 44/2006 "Tax Clearance Procedures Grants, Subsidies and Similar Type Payments".

6. OTHER TRADING ACTIVITIES

	Restricted funds **€**	**Unrestricted funds** **€**	**Total 2024** **€**	Total 2023 **€**
Raffles and Lotteries	30,403	12,265	**42,668**	38,705
Campaigns and Appeals	-	2,567	**2,567**	4,229
Fundraising Events	-	100,380	**100,380**	96,475
	30,403	115,212	**145,615**	139,409

7. INTEREST INCOME

	Restricted funds	**Unrestricted funds**	**Total 2024**	Total 2023
	€	**€**	**€**	**€**
Interest Income	-	20,768	**20,768**	4,271
	-	20,768	**20,768**	4,271

8. OTHER INCOME

	Restricted funds	**Unrestricted funds**	**Total 2024**	Total 2023
	€	**€**	**€**	**€**
Miscellaneous Income	-	24,872	**24,872**	22,950
	-	24,872	**24,872**	22,950

9(a). EXPENDITURE ON CHARITABLE ACTIVITIES

	Activities Undertaken Directly	**Grant funding of activities**	**Support costs (Note 9(b))**	**Total 2024**	Total 2023
	€	**€**	**€**	**€**	**€**
Activity					
Information & support	143,690	-	585,822	**729,512**	676,729
Training & education	1,686	-	299,075	**300,761**	354,673
Awareness	80,863	-	155,014	**235,877**	236,821
Advocacy	-	-	112,621	**112,621**	103,586
Research	1,500	68,453	26,718	**96,671**	111,278
	227,739	68,453	1,179,250	**1,475,442**	1,483,087

	Restricted funds	**Unrestricted funds**	**Total 2024**	Total 2023
Activity	**€**	**€**	**€**	**€**
Information & support	581,943	147,569	**729,512**	676,728
Training & education	225,016	75,745	**300,761**	354,673
Awareness	147,398	88,479	**235,877**	236,821
Advocacy	82,367	30,254	**112,621**	103,586
Research	34,369	62,302	**96,671**	111,279
	1,071,093	404,350	**1,475,442**	1,483,087

Awareness expenditure includes a non-cash donated service from Connelly Partners in relation to the promotion of a public awareness campaign during the year (See Note 4).

9(b). ANALYSIS OF SUPPORT COSTS AND GOVERNANCE COSTS

Charitable activities Charge for financial year	**2024** **€**	2023 €	**Basis of allocations**
Governance costs	**40,522**	36,290	No. Activities
Wages & Salaries	**966,634**	881,266	Direct costs
Information Technology	**20,142**	19,611	No. Activities
Recruitment/Training other staff costs	**10,774**	10,736	Direct costs
Travel & Subsistence	**21,643**	21,229	Direct costs
Rent and Building mgmt. services	**69,563**	66,274	Direct cost
Office Expenses	**36,371**	34,881	Direct cost
Depreciation	**13,601**	29,804	
Total	**1,179,250**	1,100,091	

10(a). EXPENDITURE ON RAISING FUNDS

	Activities Undertaken Directly **€**	**Support costs (Note 10(b))** **€**	**Total 2024** **€**	Total 2023 €
Expenditure on raising funds	83,192	224,508	**307,700**	239,306
	83,192	224,508	**307,700**	239,306

	Restricted funds **€**	**Unrestricted funds** **€**	**Total 2024** **€**	Total 2023 €
Raising donations, legacies, corporate donations & regular giving	200	-	**200**	200
Fundraising activities – campaigns, appeals and events	15,104	67,888	**82,992**	56,047
Support costs (Note 10(b))	700	223,808	**224,508**	183,059
	16,004	291,696	**307,700**	239,306

10(b). ANALYSIS OF SUPPORT COSTS AND GOVERNANCE COSTS

Fundraising activities **Charge for financial year**	**2024** **€**	2023 €	**Basis of allocations**
Governance costs	9,511	6,886	No. Activities
Wages & Salaries	200,732	140,274	Direct cost
Information Technology	4,740	4,157	No. Activities
Recruitment/Training and other staff costs	4,837	23,859	Direct cost
Travel & Subsistence	550	1,257	Direct cost
Office Expenses	4,138	6,626	Direct cost
Total	**224,508**	**183,059**	

11. TAXATION

No charge to taxation arises due to the charitable status of the company. The company is registered as a charity with the Revenue Commissioners under CHY No. 6170.

12. EMPLOYEES AND REMUNERATION

	2024	2023
Average number of persons employed	23	22
Service delivery	14	13
Fundraising	4	3
Administration	3	3
Training	2	3
	23	22
The staff costs comprise:	**€**	**€**
Information & Support	401,054	350,750
Training & Education	190,206	188,040
Awareness	101,517	93,879
Advocacy	93,841	87,093
Research	19,806	17,956
Administration	156,806	139,498
Fundraising	199,916	139,541
Other Compensation Costs	4,220	4,783
	1,167,366	1,021,540
Included in the above are costs as follows:		
Employer's PRSI	105,924	91,975
Contributions to pension scheme (Note 23)	65,007	52,868

The number of employees whose salaries (excluding employer pension contributions) were greater than €60,000 were as follows:

	2024	2023
€60,001 - €70,000	2	2
€70,001 - €80,000	1	-
€80,001 - €90,000	-	1
€90,001 - €100,000	1	-

The total remuneration for key management personnel for the financial year amounted to €207,618 (2023: €189,385). Remuneration includes salaries, employer PRSI and pension contributions.

Key management personnel of the Company comprise the Chief Executive Officer and the Director of Services.

12. EMPLOYEES AND REMUNERATION (continued)

Directors' remuneration and transactions:
No remuneration or other benefits have been paid or are payable to any directors during the year. Reimbursement for vouched expenditure of €77 was paid during the financial year (2023: €433).

13. NET INCOME

	2024 **€**	2023 €
The net income for the financial year is arrived at after charging/(crediting):		
Directors' remuneration and emoluments	-	-
Operating Lease	24,131	21,183
Depreciation	13,601	29,804
Auditors' remuneration for external audit services	18,635	18,081
Bank deposit interest	(20,768)	(4,271)

14. FIXED ASSETS

	Premises **€**	**Fixtures & Fittings** **€**	**Computers & Equipment** **€**	**Total** **€**
Cost				
At 1 January 2024	122,470	63,089	134,449	320,008
Additions	-	468	6,542	7,010
Disposals	-		(12,226)	(12,226)
At 31 December 2024	122,470	63,557	128,765	314,792
Depreciation				
At 1 January 2024	20,050	60,638	116,774	197,462
Charge for during the year	1,225	940	11,436	13,601
Disposals	-	-	(12,226)	(12,226)
At 31 December 2024	21,275	61,578	115,984	198,837
Net book value				
At 31 December 2024	101,195	1,979	12,781	115,955
At 31 December 2023	102,420	2,451	17,675	122,546

15. INVESTMENTS

	2024	2023
	€	€
Investments maturing in more than one year	344,559	890,423
Short-term investments	770,424	221,330

The company holds both short-term investments and long-term investments. All funds are invested in interest-bearing deposits with financial institutions, with a notice period exceeding three months.

16. DEBTORS: Amounts falling due within one year

	2024	2023
	€	€
Trade Debtors	69,575	182,430
Prepayments	36,694	36,925
Other Debtors	68,310	27,512
	174,579	246,867

All debtors are due within 30 days from the issue date of the invoice.

17. CASH AT BANK AND IN HAND

	2024	2023
	€	€
Cash at bank and in hand	658,447	371,215
	658,447	371,215

18. CREDITORS: Amounts falling due within one year

	2024	2023
	€	€
Trade Creditors	75,884	24,919
Accruals	36,949	34,941
Deferred Income	121,910	157,634
PAYE/PRSI/USC/Pension	28,650	22,814
Other Creditors	4,250	2,349
	267,643	242,657

The terms of trade creditors vary between on demand and 30 days. No interest is payable on trade creditors.

19. DEFERRED INCOME

	2024	2023
	€	€
Balance at beginning of year	157,634	40,735
Amount received during the year	48,901	157,634
Amount released to SOFA during the year	(84,625)	(40,735)
Balance at end of year	121,910	157,634

19. DEFERRED INCOME (continued)

Total deferred income of €121,910 includes €69,304 relating to a restricted grant from Angelini Pharma which will be recognised as income as the performance conditions are met. Additionally, a deferred income of €43,493 relates to HSE CHO7 income relating to 2025 which was invoiced in 2023. It also includes membership fees received of €9,112 relating to 2nd and 3rd year of membership (based on estimate, assuming the membership income received has average terms of 3 years).

20. FINANCIAL INSTRUMENTS

The carrying value of the company's financial assets and liabilities are summarised by category below:

	2024	2023
	€	€
Financial assets		
Measured at undiscounted amounts receivable		
· Debtors (Note 16)	174,579	246,867
Financial liabilities		
Measured at undiscounted amount payable		
· Creditors (excluding deferred income and PAYE/PRSI/USC pension) (Note 18)	117,083	55,502

21. ANALYSIS OF FUNDS

	Opening Balance 1 January 2024	Income	Expenditure	Transfers	**Closing Balance 31 December 2024**
	€	€	€	€	**€**
Restricted Funds					
Health Service Executive	9,875	827,867	(881,149)	58,282	**14,875**
SSNO Funding (Pobal)	-	84,993	(84,993)	-	-
Toyshow Appeal Funding	13,011		(13,011)	-	-
Angelini Funding	-	40,587	(40,587)	-	-
Donated Services	-	17,112	(17,112)	-	
Restricted Donations	-	15,000	(12,040)	-	**2,960**
Other Grants	21,327	5,000	(7,800)	-	**18,527**
In Memory Fundraising	80,894	1,682		-	**82,576**
Research funding scheme	-	30,403	(30,403)	-	
	125,107	1,022,644	(1,087,095)	58,282	**118,938**

21. ANALYSIS OF FUNDS (continued)

	Opening Balance 1 January 2024	Income	Expenditure	Transfers	**Closing Balance 31 December 2024**
Unrestricted funds					
Operational Reserve	984,617	947,094	(612,680)	(221,866)	**1,097,165**
Designated					
Premises reserve	100,000	-		-	**100,000**
Research Provision	150,000	-	(53,854)	53,854	**150,000**
Research Officer	-	-	-	90,000	**90,000**
Awareness Campaigns	100,000	-	(29,512)	29,512	**100,000**
Strategic Plan Implementation	150,000	-		(9,782)	**140,218**
	500,000	-	(83,366)	163,584	**580,218**
Total Unrestricted Funds	1,484,617	947,094	(696,046)	58,282	**1,677,383**
Total Funds	1,609,724	1,969,738	(1,783,141)	-	**1,796,321**

HSE-funded services are only partially funded and €58,282 (2023: €74,020) has been transferred from the unrestricted Operational Reserve to meet the full cost of providing the services.

€14,875 of HSE funds (2023: €9,875) is made up of National Lottery grants which are being carried forward for use in 2025.

Other restricted grants totalling €18,527 (2023: €21,327), including €5,000 from the Hospital Saturday fund are also carried forward to be utilised in 2025.

The In-Memory fundraising balance carried forward of €82,576 (2023: €80,894) relates to total funds raised in 2021, 2022, 2023 and 2024 specifically for the purpose of launching a new service to provide wearable seizure-monitoring devices to service users. This service was launched in 2024.

The Board has designated reserves for utilisation in special strategic activities including undertaking epilepsy awareness campaigns; providing funding for current and future research projects; and for upgrading/relocating the charity's head office in Crumlin. The Board also maintains a reserve to facilitate implementation of the organisation's Strategic Plans.

21. ANALYSIS OF FUNDS (continued)

In 2024, the Research reserve was reduced by €53,855 to meet the cost of current research grants in the year. It was replenished to €150,000 to meet the cost of future anticipated research investments. The Awareness reserve was reduced by €29,512, representing costs associated with International Epilepsy Day campaign. It was also replenished to €100,000 for provide for future annual campaigns. The Strategic Plan implementation reserve was reduced by €9,782, representing the cost of a new staff role approved by the board in December 2023.

The Board also approved the creation of a new designated reserve of €90,000 to support the employment of a new Research Officer staff position from 2025, utilising an unrestricted donation received in December 2024.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Restricted funds €	Unrestricted funds €	Closing Balance €
Fixed Assets		115,955	115,955
Current Assets	240,848	1,707,161	1,948,009
Liabilities	(121,910)	(145,733)	(267,643)
	118,938	1,677,383	1,796,321

In respect of prior year

	Restricted funds €	Unrestricted funds €	Closing Balance €
Fixed Assets	-	122,546	122,546
Current Assets	282,741	1,447,094	1,729,835
Liabilities	(157,634)	(85,023)	(242,657)
	125,107	1,484,617	1,609,724

23. RETIREMENT BENEFITS

The company operates a defined contribution scheme. The assets of the scheme are held separately from those of the company in an independently administered fund. The pension cost, €65,007 (2023: €52,868) is charged to the Statement of Financial Activities in the financial year in which it arises. There was €10,578 payable at the financial year-end (2023: €6,707).

24. CONSTITUTION

The company is limited by guarantee and does not have a share capital. Every member of the company undertakes, if necessary, during the time they are a member or within one year after they cease to be a member, to contribute to the assets of the company an amount not exceeding €1.

25. COMMITMENTS

The company has committed to spending the following on research projects in the coming years:

	2024 €	2023 €
Within one year	9,000	75,954
Between two and five years	-	9,000
Total	9,000	84,954

Operating Lease Commitments

Total future minimum lease payments under non-cancellable operating leases are as follows:

	2024 €	2023 €
Within one year	24,131	22,660
Between one and two years	16,396	36,605
Total	40,527	59,265

26. RELATED PARTY TRANSACTIONS

During the financial year, transactions took place between the company and Camphill Communities of Ireland. This transaction involved the provision of training services for €1,200. A director of the company, Ambrose Kealy, also serves as a director of Camphill Communities of Ireland.

As set out in Note 12, reimbursement for vouched expenditure of €77 was paid during the financial year to directors.

27. SUBSEQUENT EVENTS

There are no significant events subsequent to the financial year end.

28. APPROVAL OF FINANCIAL STATEMENTS

The financial statements were approved by the Board of Directors on 20th May 2025.

Paul Fahey
Director

Paul Kehoe
Director