

Brainwave The Irish Epilepsy Association
T/A Epilepsy Ireland

Reports and Financial Statements
for the financial year ended
31 December 2023

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**REPORTS AND FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

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DIRECTORS AND COMPANY INFORMATION

DIRECTORS

Ms C. Grieve (Chairperson)
Ms H Behan
Mr A. Chalke
Mr M. Curran
Mr P. Fahey
Ms M. Fitzsimons
Mr A. Kealy
Mr P. Kehoe
Ms A. Kilroy
Prof M. King
Ms A. Maguire
Ms N. Nagle
Ms C. O'Dea
Ms N. Saarsteiner

SECRETARY AND REGISTERED OFFICE

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AUDITORS

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BANKERS

Allied Irish Banks plc
Bank of Ireland
Permanent TSB

SOLICITORS

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Warrington House,
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CHARITY NUMBER

CRA (Charities Regulator): 20010553
CHY (Revenue): 6170

COMPANY REGISTRATION NUMBER

77588

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DIRECTORS' REPORT

The directors present their annual report and the audited financial statements of the company for the financial year ended 31 December 2023.

OBJECTIVES AND ACTIVITIES

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

About Epilepsy

Epilepsy is a group of neurological disorders, characterised by recurrent, unprovoked seizures involving abnormal electrical activity in the brain. The condition affects approximately 45,000 people in Ireland, including an estimated 10,000 - 15,000 children. Epilepsy is a treatable condition in most cases, and today, up to 70% of people can become seizure-free through medication and self-management approaches. In some cases, surgery and neurostimulation may be used to achieve seizure control.

However, there are an estimated 2,000 new diagnoses of epilepsy annually, and up to 15,000 people are living with uncontrolled seizures. For this group in particular, epilepsy can be a source of long-lasting and often hidden disability. The condition can affect all aspects of a person's life including learning, employment, social & family life, psychological & cognitive functioning, and independent living. People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications and for many, the social stigma that can be associated with it. The financial burden of epilepsy is also significant. More than €15 billion is spent annually on the treatment of epilepsy in Europe, and Epilepsy Ireland estimates the total cost (direct & indirect) of epilepsy in Ireland is c. €584m per annum, equating to almost €15,000 per person.

There is also an increased risk of death associated with epilepsy, due to causes such as status epilepticus (prolonged seizures), injury/ trauma, or the underlying cause of the seizures. Sudden Unexpected Death in Epilepsy (SUDEP) is a poorly understood fatal complication of epilepsy, which is one of the most common causes of death.

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 over 50 years, we have remained focused on reducing the burden of epilepsy for those living with the condition and their families. Our current (2022-2026) Strategic Plan defines six key strategic aims, which along with our vision and mission, is guiding all that we do as an organisation 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 ensuring the structures are in place to meet objectives.

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These aims are further broken down into 13 key objectives, which form the basis of our annual operational plans, budgets and monitoring. These objectives are also the format used throughout this Directors' Report.

This strategy was developed during 2021 in consultation with internal and external stakeholders, including service users, members, staff, board, volunteers and representatives from the medical & scientific community. The plan was approved by the Board in 2022, and publicly launched at the 2022 annual conference in Dublin.

The plan is an ambitious and detailed roadmap for the development and continual improvement of the organisation and our services & activities. It aims to respond to the growing demand for our services and the changing needs of our community, and to deliver outcomes that positively impact our service-users.

During its development, close attention was paid to the organisation's strengths, weaknesses, opportunities and threats; the external environment in which the organisation operates; and to the financial resources available - or likely to be available - to support the implementation of the plan. Indeed, effectively resourcing the plan is recognised by the Board as being the most significant challenge in achieving the agreed objectives.

2023 was the second year of our strategic plan and in our Achievements & Performance section (below), we detail the activities, challenges and achievements for the year under each of the organisation's six strategic aims and the 13 key objectives contained within them.

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.

Support and education services for people with epilepsy, their families and carers are the core of our work at Epilepsy Ireland. Information and education are crucial tools in overcoming fear and misunderstanding about the condition. Our services aim to empower people with epilepsy and their families at all stages of their epilepsy journey. Our work also extends to health professionals, schools, employers, and the public.

Our services include one-to-one support, educational programmes, individual & group-based self-management programmes, community and hospital-based outreach services, support groups, events & seminars, a range of resources & publications and personal advocacy support.

These services are provided by a team of 11 Community Resource Officers (CROs) based in Dublin, Cork, Galway, Shannon, Kilkenny, Killarney, Tullamore, Letterkenny/Sligo and Navan and by our National Information Officer. The team works to meet the needs of people within their communities and are supported by the Epilepsy Ireland-funded Advanced Nurse Practitioner post, based at Beaumont Hospital.

Our services continued to experience high demand in 2023, with a total of 19,975 contacts across the year (2022: 19,917). This includes 9,533 individual contacts via phone, email, zoom or in-person meetings (2022: 10,463) while 10,442 availed of support/ training in a group setting (in-person and online) offered throughout the year (2022: 9,454).

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The Living Well with Epilepsy programme is a core element of our service targeted at adults/ parents who are newly diagnosed with epilepsy. Commonly referred to as the “toolkit”, the programme is delivered by our CRO team, with the aim of empowering service users in better understanding epilepsy to provide them with the tools needed to self-manage the condition. In 2023, 233 individuals availed of the Living Well with Epilepsy Programme (2022: 365).

Our local support groups have been a traditional mainstay of our service. The groups enable people living with epilepsy – or those who are caring for a loved one with epilepsy – to meet with others living with or supporting a person with the condition. Through this, attendees can discuss their condition in a safe environment, supported by their peers and local CRO. Support groups continued to be run online and in-person throughout the year with 42 sessions held (2022: 33). However, our long-running STEPS self-management programme experienced a decline in demand in 2023 with one programme active for adults with epilepsy and one for parents of children with epilepsy.

Several special events were organised during the year, most notably a range of activities around the International Epilepsy Congress in September which was held in Dublin (see 3.1 below). Our annual Family Fun Day took place in June, with Fota Island Wildlife Park being the destination this year. The day enables families and children with epilepsy to come together in a fun environment to meet each other, and over 150 people attended in 2023. Other events held in 2023 included:

- Life-Balance and Self-Care on your journey with epilepsy, a new support programme delivered over five sessions.
- Employment Rights and Job Search Tips workshop
- Memory and Study Skills workshop for teens with epilepsy
- Epilepsy and Menopause
- Seizure Detection Devices workshop

Six Joint Epilepsy Education Sessions for adults with a new diagnosis of epilepsy were co-delivered by Epilepsy Ireland CROs and HSE Advanced Nurse Practitioners. These events have proven to be a successful model of collaboration between EI and HSE professionals, and in 2023, we expanded the idea to provide two similar events for parents of children with new diagnoses. Using our relationships with the medical community and contacts within the community, we will continue to host special ‘themed’ events throughout 2024.

Epilepsy Ireland funds an Advanced Nurse Practitioner (RANP) post at Beaumont Hospital focused on the care of women with epilepsy, with outreach clinics in the National Maternity Hospital, the Rotunda, the Coombe and Our Lady of Lourdes Hospital in Drogheda. Included in individual contacts are 1,111 contacts with the RANP in 2023 (2022: 1,334). In addition to clinical work, the RANP provides specialised support for our services team, co-delivers online epilepsy education sessions alongside our CROs and contributes to the review and updating of our information materials. Wider aspects of the RANP’s work in 2023 included the hosting of a special event focussed on epilepsy and menopause and the initiation of the Epilepsy Journal Club for clinicians and EI staff.

Epilepsy Ireland also works closely in supporting professionals whose work brings them into contact with people living with epilepsy. This includes doctors, nurses, social workers, teachers, healthcare professionals and others. We distribute a range of information resources including our ‘Education Information Pack – An Epilepsy Resource for Pre-schools, Schools, and Colleges’ and our ‘Epilepsy in the Workplace’ guide. Alongside this, we also provide epilepsy awareness presentations for schools, medical institutions, workplaces and other settings where a need is recognised. In 2023, we delivered a total of 152 talks to schools, preschools, and other education settings with 3,731 people attending (2022: 119; 3,271).

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Sadly, 2023 was the final year of Training for Success (TFS), a service that had been a fixture of our work for almost 25 years. TFS was a QQI Level 5 one-year course at ATU Sligo aimed at supporting people with epilepsy whose condition may have impacted on their education outcomes. The course was of huge benefit to hundreds of young people with epilepsy over the years, with many pointing to their participation in the course as a turning point in their lives. However, in recent years, with attitudes to epilepsy changing for the better, many more adult education courses becoming available across the country, and greater accessibility/ inclusiveness for students with epilepsy to pursue their chosen course, interest in the course had waned and the decision was taken that the course would end in 2023. In addition, recent changes with IT Sligo becoming a Technological University would have seen the course change significantly, losing some of its most unique aspects.

While it was sad to see the course ending, we can be proud of the impact TFS made and the positive legacy that it has had in the lives of so many. Upon completion of the final term, we undertook a survey of past students and its impact was best exemplified in the finding that 100% of respondents agreed that TFS helped them achieve their goals. The decision to end TFS has enabled us to increase our focus and resources on another aspect of our training service – the provision of much needed training in Epilepsy Awareness and the Administration of Buccal Midazolam, discussed in 3.2 below.

1.2 Identify and fill gaps in epilepsy service needs.

Following on from the introduction of new service developments in 2022 such as 'Get ChARTy' and 'Mid-Morning Mindfulness', innovations continued in 2023, with a particular focus on increasing our engagement with young people/ children with epilepsy and their family members.

These included online groups such as 'Teen Time', Young Adult Meet-Ups and creative workshops for siblings of children with epilepsy. These activities were supported by a grant from the RTE Toy Show Appeal.

Although epilepsy is a common condition, an experience shared by many of our service users is that they never knew anyone else with epilepsy growing up, and based on this feedback, Teen Time was established. Teen Time is an online event aimed at bringing young people (13-17 years old) with epilepsy from across Ireland together in a safe environment where they can discuss their own personal journey with epilepsy and the challenges faced with other teens who understand what they're going through. Three events were held during the year, starting in September.

Young adulthood can also be a particularly challenging time for those living with epilepsy. Life events such as facing exams, experiencing increased independence, starting out in careers, or building new relationships are all changes that can have a knock-on effect on a person's epilepsy. Monthly Meet Ups were set up to provide young adults (18-24 years old) with a much-needed opportunity to meet with others of a similar age who are living with epilepsy, discuss their experiences and challenges, and hear from others who are also navigating or have already navigated these challenges in a shared learning environment. Seven events were held in 2023.

When parents/ guardians are caring for and supporting a child with epilepsy, there can be a knock-on impact for that child's siblings, particularly where the condition is complex. Due to the challenges that epilepsy can bring to a family, siblings can sometimes feel isolated or feel worried about their loved one's condition. Our new workshops for siblings of children with epilepsy provides children (8-12 years old) with an opportunity to participate in online fun and games, while also discussing concerns they might have about their sibling's long-term health condition. The workshops can help a child feel less isolated and concerned and help to increase their understanding of their sibling's epilepsy. Five events were held during the year.

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The 'Get ChARTy' project, first introduced in 2022, is specifically targeted at children/ young teens with epilepsy (8-12 years) and in 2023, seven sessions were held. These online events enable children with epilepsy to meet with others informally and do some art at the same time. The sessions were facilitated again by Creative Art Therapist, Nichola Mooney and supported by our CROs. Participants also had the chance to meet each other face to face at the annual family fun day.

All these new initiatives aimed at children and young adults will continue in 2024. In addition, funding was secured through a grant from Angelini Pharma for 2024-2026 to further develop our service offerings through the creation of a Young Epilepsy Programme (YEP), to be developed and rolled out by a new Youth Resource Officer. This major development will ensure that Epilepsy Ireland can continue to meet the needs of these groups into the future.

Another significant development was the launch of EpiLearn, our organisation's first foray into the world of e-learning during National Epilepsy Week in May. The app was developed in collaboration with healthcare eLearning specialists, Aurion Learning, using their latest learning platform, ByteKast and is available in Apple, Android and desktop formats. It complements existing support services and information resources by adding a new digital, interactive layer for those seeking to learn more about epilepsy. The app provides bite-size information on epilepsy, structured into pathways of learning that features videos, quizzes, and practical exercises. The app was launched with one pathway, designed to give users an introduction to epilepsy and features four distinct levels focussed on understanding epilepsy, seizure types, seizure triggers, medications and seizure safety. We look forward to building new resources within the app in 2024.

Online mindfulness sessions, first introduced in response to (adult) service user needs in 2022, continued in 2023 and again proved to be a popular and successful addition to our services portfolio. 32 sessions were held during the year.

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 crucial strategic aim for our organisation and ensures that the board, management, and staff are mindful at all times of the importance of understanding the needs and lived experience of the epilepsy community and planning our work accordingly.

In 2023, the Board approved the establishment of the Epilepsy Ireland Service-User Consultation Group. The group has a defined Terms of Reference and is made up of people who have used our services, been involved in our work, or volunteered in the past. The purpose of the Group is to provide input, feedback, and new ideas into the operational activities of Epilepsy Ireland, that helps management and the Board ensure that we continue to meet the needs of people with epilepsy and their families in accordance with our vision, mission and values.

The role of the Group will include input and feedback on matters such as research priorities, awareness themes, advocacy priorities, EI communications, events, services provision gaps and more. At year end, 11 invited service users/ volunteers had confirmed their participation, and an inaugural meeting was scheduled for early 2024.

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In August 2023, we launched a wide-ranging survey of individuals who have engaged with any of our activities over the past two years. The survey was an opportunity for service users/ volunteers to provide feedback on all aspects of our work - support services; training and education programmes; awareness and advocacy campaigns; and activities related to epilepsy research. The survey was shared across our website, publications, and social media channels. 184 fully complete and valid responses were received with most respondents being people with epilepsy (48%) and parents of child/family member of a person with epilepsy (31%). The survey was a very beneficial exercise and provided plenty of food for thought on different aspects of our work, but we were heartened by the overwhelming positive response that respondents outlined. For example:

- 98% of those surveyed would recommend Epilepsy Ireland to those with similar needs.
- 94% of those surveyed would rate their experience of Epilepsy Ireland as either very positive (74%) or positive (20%)

We will conduct the survey again in 2024 to ensure we continue to accurately capture the experience and feedback of everyone who engages with any of our activities.

As part of the activities for the International Epilepsy Congress, a special international Youth Summit for young people with epilepsy was arranged by the International Bureau for Epilepsy, supported by Epilepsy Ireland. The Summit brought together inspiring young people with epilepsy, from all over the world – including eight Epilepsy Ireland volunteers. The event not only highlighted the challenges faced by young people living with epilepsy but also provided a platform for them to share their experiences, knowledge, and advocate for a better future. Sessions included self-care, challenges of epilepsy, and epilepsy research. Our delegates made an enormous impact and were an inspiration to others in attendance – thank you to Jack, Cara, Lucy, Melissa, Jonathon, Sophie, Grace and Rachel.

Epilepsy Ireland is a membership-based organisation, and offers a range of different membership options through one-, three- and five- year packages. Our members make our collective voice much stronger and louder and we encourage everyone with an interest in the condition to become an Epilepsy Ireland member. The current membership structure was introduced in 2018, and at the end of 2023, a review was initiated to examine the suitability of the current approach, and how the membership model could be improved. The work will be completed in 2024.

Volunteering

Volunteers are essential to the work of Epilepsy Ireland. Although core services are provided exclusively by paid staff, volunteers work with the staff team to help raise awareness of the condition (e.g. via personal stories, media engagements), support advocacy goals and engage with epilepsy research.

Volunteer-led fundraising such as organising events, participating in EI-organised events, campaigns and collections or representing EI in marathons, challenges etc. is also vital in ensuring we continue to work towards our mission. We are grateful for the support of hundreds of fundraising volunteers each year – see 5.1 below.

The Volunteer of the Year award is a small token of appreciation of the outstanding efforts an individual or a group of individuals have undertaken in support of Epilepsy Ireland and highlights the importance of volunteering within our organisation. Selecting the award winners reminds us how fortunate Epilepsy Ireland is to have the support of incredible people from across the country who are committed to both raising awareness of epilepsy and raising the funds that are needed to continue our journey towards a society where no person's life is limited by epilepsy.

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In 2023, there were two recipients of the award – Mark McGuire from Co. Kildare and Rachel Langan from Co. Galway. Mark was recognised for his incredible fundraising and awareness-raising efforts for Epilepsy Ireland, scaling Kilimanjaro in the name of his son Ciáran who was diagnosed with epilepsy in 2021. Rachel was recognised for her advocacy work in highlighting the issues around deferred examinations for Leaving Cert students who experience seizures during their exams. Her contributions to our campaign (see 4.1 below) provided real life context of the need for better accommodations and were instrumental in achieving the change that was finally secured in 2023. We are proud to call Mark & Rachel our volunteers of the year!

One of the highlights of 2023 was seeing our member and volunteer Wayne O'Reilly from Wexford receiving a Golden Light Award from the International Bureau for Epilepsy on the main stage at the International Epilepsy Congress. The IBE Golden Light Awards are bi-annual awards that recognise young people affected by epilepsy – either because they have epilepsy or have made a significant positive impact on the lives of others who have the condition. Wayne was one of just three young people from across the globe selected in 2023, recognising his work over many years in supporting epilepsy awareness and fundraising.

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 educational professionals, and the medical/ scientific community to improve the care of people with epilepsy and to increase knowledge of the condition. Below we highlight the main activities in 2023 under each of the four objectives of the 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 acknowledges that it has an important role to play in the development of epilepsy services in Ireland and we have a long and successful track record of working with HSE services to improve and expand upon service provision. Our strategic objective of advancing a community-based, patient-centred model of care is closely aligned with the HSE's Sláintecare strategy, which aims to reform health services, including through improved integration and co-ordination across all care settings; a focus on early intervention; and individualised, holistic person-centred care designed around the needs of the patient. In applying these principles to epilepsy care, our community-based services are an important component in the wider care of people with epilepsy.

One way we are working towards this goal is through the Joint Education Sessions, described above in section 1.1. Originally funded through the Sláintecare Integration fund, we have continued to organise these education programmes alongside HSE services, even after the funding has expired. The programme is aimed at newly diagnosed adults and parents of newly diagnosed children and co-delivered by epilepsy specialist nurses and Epilepsy Ireland CROs. We believe the project is an excellent model of collaboration which delivers an effective early intervention for people coming to terms with an epilepsy diagnosis. Although eight group sessions were held in 2023, there is scope to develop the service further, if renewed funding was available.

However, there has been limited opportunity to advance the overall strategic objective, largely due to a lack of progress on Sláintecare implementation. We continue to maintain strong links with specialist epilepsy services, both paediatric and adult across the country. This includes our funding for the Registered Advanced Nurse

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Practitioner (RANP) for Women with Epilepsy based at Beaumont Hospital, also discussed in section 1.1, as well as ongoing engagement with the National Epilepsy Clinical Care Programme and Epilepsy Electronic Patient Record (EPR) Governance Group.

Other collaborations during 2023 aimed at improving the care of people with epilepsy and knowledge of the condition included:

- Financially supporting and working with a range of interested stakeholders on the health information and education needs of women with epilepsy project outlined in 3.3 below.
- Working closely with the Irish Epilepsy League on advocacy issues including Free Travel and deferred exams (see 4.1)
- Collaboration with international organisations such as SUDEP Action, Infantile Spasms Awareness Network and Epilepsy Advocacy Europe on specific campaigns and with a variety of national organisations including the Disability Federation of Ireland, the Neurological Alliance of Ireland, OACS Ireland and many others.
- Collaboration with research institutions on epilepsy-related projects and events, such as RCSI (FutureNeuro), DCU and others as discussed in section 3.4. We also continued work with the Department of General Practice at UCC on developing a Consultation Guide for people with epilepsy and GPs designed to improve the patient experience at GP appointments.
- Participation in the HPRAs' patient forum and the Department of Health's Valproate Stakeholder Group.

However, the most significant and exciting collaboration of 2023 was the holding of the International Epilepsy Congress in Dublin in September. The Congress is the largest international scientific epilepsy meeting, and over 3,000 healthcare and scientific professionals from across the global epilepsy community were in attendance to share expertise and knowledge with their colleagues.

The congress is organised by the International Bureau for Epilepsy and International League Against Epilepsy every two years and as the local epilepsy organisation in the host country, we were delighted to collaborate in the organisation of the event.

Historically, the congress has been aimed at the scientific and medical community but in 2023, we were delighted to bring a public-facing element to the event. EI arranged two public sessions featuring more than a dozen of the leading global experts, presenting directly and in plain-English to people with epilepsy and their families on some of the hot topics featured on the main scientific agenda. Close to 400 people attended in-person across two nights, with approximately 300 people tuning in online each night.

The event also featured a special Youth Summit (see 2.1 above) and in another important new development, the majority of scientific sessions featured at least one expert-by-experience speaker, including several from Ireland. We hope that these patient-centric developments will continue to be a fixture of the congress as it travels across the globe in future years.

There were many other memorable highlights from the week, including the Taoiseach's opening address and State Reception for the local and international organisers. On both occasions, he paid tribute to the work of Epilepsy Ireland, highlighting in particular the strong history and contributions of the organisation in working with Government and policy-makers to improve the lives of people with epilepsy in Ireland.

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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 been providing a training programme in Epilepsy Awareness & the Administration of Buccal Midazolam (BM) to health and allied health professionals. Trainees include healthcare workers, education staff like teachers and SNAs, bus escorts, employers/ employees (working alongside a person with epilepsy), community workers, facilitators of extra-curricular activities in the community and more.

BM is an emergency rescue medication administered by caregivers in the community to stop a seizure after it has started. The medication prevents seizures from becoming more serious, reduces hospitalisation and minimises disruption to the person's daily life. Our programme trains participants in developing a greater understanding of epilepsy and the role of the emergency rescue medication and provides instruction in the correct administration of BM.

The training is delivered by Epilepsy Ireland's training team and CROs, adhering to the guidelines and training standards developed by the Joint Epilepsy Council of the UK and Ireland and updated by the Epilepsy Specialist Nurses Association (ESNA) 2019 guidelines. On successful completion of the training, trainees are issued a certificate of completion which is valid for two years. Since 2020, we offer the training both online and in-person. In-house training sessions are also provided.

The programme has grown over the years to become a core part of our work at Epilepsy Ireland. All our trainers have completed 'train the trainer' training and undertake bi-annual refresher training from Quarriers, the Scottish Epilepsy Centre. A major development in 2023 was the reassignment of an existing staff member to the training team to meet demand for the programme and enable the service to grow further. In 2023, training fees were increased for the first time since 2009 to cover increasing costs. In total, 2,791 professionals took part in this important training through 214 training sessions (2022: 2,536; 236).

In addition to formal training programmes, our Community Resource Officers also deliver BM information sessions for parents and family carers in all regions of the country to help ensure that parent/ carers know how to correctly administer this commonly prescribed medication. In 2023, 43 individual courses were delivered by our team with 183 parents/carers attending. (2022: 39;171)

Epilepsy awareness talks continued to be delivered in schools, organisations and workplaces both online and in-person. A total of 152 sessions were held across all settings with 3,731 attendees, compared to 119 sessions/ 3,271 attendees in 2022.

Other training was also delivered in several institutions including NRH (nursing staff), Athlone IT (Nursing students), UCD (Nursing), St James's Hospital (Nursing staff), RCSI (GP students), TCD (college staff) and paramedic students.

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

2023 was a significant year for our Research programme as we surpassed the €1.5 million mark in total investment in epilepsy research projects since the launch of our funding scheme in 2009. This is a considerable investment for an organisation of our size and would not have been possible without the continued support of donors and supporters across the country. Over that time, 23 different high quality, high-impact Irish research projects have been supported across basic science and clinical, psychosocial, genetic and health services research.

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There are currently eight active projects and 2023 saw one new project begin, an RCSI-led project to identify, alongside women with epilepsy, their families and healthcare professionals, the specific health information needs of women with epilepsy along the preconception to postpartum continuum. The project will also develop evidence-based resources to support women and health professionals during this period.

Led by Dr Aisling Walsh at RCSI's Department of Public Health and Epidemiology, the project is funded under the Health Research Board's Applied Partnership Awards, with Epilepsy Ireland co-funding €15,000 as one of the project's two designated knowledge-users. The other knowledge-user is the HSE's National Women and Infants Health Programme, and additional research team members include: Sinead Murphy & Yvonne Owen, Registered Advance Nurse Practitioners in epilepsy; Profs Anne Matthews and Veronica Lambert, DCU School of Nursing; Dr Deirdre Daly, TCD School of Nursing and Midwifery; Prof Kathleen Bennett, Head of Data Science Centre RCSI; Dr Fergal O'Shaughnessy, Senior Pharmacist, Rotunda; Killian McGrane, HSE and Claire Daly, PPI contributor. We believe that the study has the potential to make a huge impact on the future care of women with epilepsy in Ireland, including those who are planning pregnancies in the future.

Epilepsy Ireland is a member of Health Research Charities Ireland (HRCI) and regularly participates in the HRCI's Joint Funding Scheme (JFS) in collaboration with the Health Research Board (HRB). Under this competitive funding scheme, successful applications are funded 50% through HRB and 50% through research charities (including Epilepsy Ireland). Although a funding round under the JFS was announced in 2023, the Board decided not to participate on this occasion, due to the record number of ongoing projects, and the financial commitments associated with them. We plan to return to participating in this excellent scheme for the next round in 2025.

In recent years, we have also partnered with the Irish Research Council (IRC) through the Enterprise Partnership Scheme (EPS). The scheme funds postgraduate and postdoctoral researchers to collaborate with an enterprise partner such as Epilepsy Ireland on a research project of mutual interest. The Enterprise Partner funds 1/3 of the research costs with the IRC funding 2/3.

In addition to the new project, the other seven ongoing EI-funded studies at the end of 2023 are:

- *Predicting and monitoring outcomes in Autoimmune Encephalitis*
Principal Investigator - Prof. Norman Delanty, RCSI (through HRB/HRCI JFS)
The study aims to find ways of predicting which people with Autoimmune Encephalitis are at the greatest risk of negative treatment outcomes, so that clinicians can better direct them towards appropriate treatments.
- *Long non-coding RNAs: regulators of epileptogenesis and potential targets for therapy*
Principal Investigator - Dr Gary Brennan, UCD (through HRB/HRCI JFS)
The study aims to identify the extent of dysregulation of long non-coding RNAs in epilepsy and then test whether these molecules can be targeted to identify novel therapeutic strategies.
- *Molecular mechanisms, therapeutic targets and biomarkers for CDKL5 Deficiency Disorder (CDD)*
Dr Omar Mamad & Erva Ghani, RCSI (through the IRC's EPS)
The study aims to document the role of micro-RNAs in CDD and enhance current understanding of the underlying cellular and molecular mechanisms in this rare epilepsy syndrome.
- *Circadian biomarkers in pre-clinical and clinical Dravet Syndrome*
Dr Cristina Reschke & Radharani Benvenuti, RCSI (through the IRC's EPS)

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The study aims to identify circadian molecular biomarkers for Dravet pathogenesis and relevant SUDEP-linked phenotypes which may predict SUDEP in this population.

- *EPIVIEWS: Exploring Patient Impact & Value in Epilepsy Wearables for Seizure Monitoring*
Dr Rob Argent & John David Dalameiro, RCSI (through the IRC's EPS)
The study will investigate the validity and impact of the popular Empatica Embrace2 wearable device for seizure detection.
- *Development of a non-invasive ultrasound stimulation approach to modulate the seizure-like firing of induced pluripotent stem cell-derived neurons from epileptic patients*
Dr Leo Quinlan & James Britton, NUI Galway (through the IRC's EPS)
This study is investigating whether ultrasonic stimulation can regulate electrical activity in the brain associated with seizures in difficult to control epilepsies like Dravet syndrome and Lennox Gastaut syndrome.
- *Epilepsy Mortality in Ireland*
Dr Yvonne Langan, St James's Hospital
See Section 3.4 below.

At year end, we were awaiting funding decisions on a number of projects we plan to collaborate on. These included two further IRC EPS projects selected by our Research sub-committee; a DCU-led study on the potential of AI-based signalling devices for dogs that would detect and inform people with epilepsy of behavioural changes in the animal that may forewarn of seizures; and a potential collaboration with FutureNeuro to run a series of events on "Brain health, epilepsy and concussion in sport" from 2024.

Research communication is an important part of our epilepsy research work and in May 2023, we collaborated with FutureNeuro to organise the *Epilepsy Research Matters – A Showcase of Irish Epilepsy Research* event at RCSI for members of the public. The event featured leading scientists, clinicians and researchers investigating epilepsy in Ireland, discussing their work to drive new discoveries and treatment of the condition. It also included a panel discussion and audience input about the future directions and priorities of epilepsy research.

We also continued to connect researchers to people with epilepsy through our communications channels and produced the annual research bulletin (magazine) for donors supporting our research activities.

Supporting patient and public involvement (PPI) in research is also an objective and we worked with two research groups to establish PPI panels for their projects. We also continued to engage with Dublin City University and RCSI on the National PPI Ignite network which aims to improve the involvement of patients and the public in research decision-making and in the research process itself.

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) is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy and where no other cause of death can be identified. There is approximately 1 case of SUDEP for every 1,000 people with epilepsy annually. Although it is still not fully understood, risk factors include having uncontrolled or frequent seizures and having generalized tonic-clonic seizures. Several other risk factors are associated with lifestyle such as avoiding seizure triggers, avoiding alcohol, and adhering to medication regimens.

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SUDEP risk management is a key aspect of our education and self-management programmes such as the Living Well with Epilepsy programme and the Joint Education Sessions described above. We also provide a booklet on 'Seizures and Safety' and have a comprehensive section on our epilepsy.ie website.

SUDEP Action Day is one of the most important days in our calendar to raise awareness of SUDEP amongst the entire epilepsy community, including healthcare professionals. In October 2023, we shared personal testimonies from families who had lost a loved one due to SUDEP. These powerful testimonies are important in raising awareness of SUDEP amongst people with epilepsy, their families, and healthcare professionals in order to encourage discussions around SUDEP and managing risks. Primarily using social media, the campaign was extremely well received with over 20,000 visits to our website across the month of October.

We also organised a patient survey to learn more about knowledge of SUDEP among people with epilepsy (and parents of children with epilepsy) and about communications between them and their healthcare team on SUDEP. The survey received feedback from 326 respondents, and some of the key findings included:

- 32% of those with epilepsy and 27% of parents/ guardians indicated that they had no prior knowledge of SUDEP.
- 82% of respondents believed that SUDEP should be discussed with people with epilepsy by medical professionals regardless of whether they are deemed at high risk or not.
- 50% believed that SUDEP should be discussed immediately on diagnosis, while 34% believed that it should be discussed within 1 year of diagnosis.

These results, alongside the many other findings within the survey will be crucial to our plans to build a national campaign to reduce epilepsy-related deaths in Ireland and some initial campaigning steps were taken in 2023 – including writing to all members of the Oireachtas informing them about SUDEP and our plans to seek a National Strategy to reduce epilepsy-related deaths. We look forward to continuing this work in 2024.

Epilepsy Ireland has partnered with UK charity SUDEP Action since 2015 on the Epilepsy Deaths Register for Ireland (EDRI). The register provides a safe and secure platform for those bereaved by epilepsy and for professionals to provide information about the deaths of people with, or suspected to have had, epilepsy. The register is a very important tool for researchers aiming to learn more about SUDEP and other epilepsy-related deaths and data feeds into an international register. As part of our activities for SUDEP Action Day in 2023, we made a specific appeal to bereaved families to provide details of their loved one to the register.

We continued to work with SUDEP Action on plans to make their evidence-based, validated SUDEP and Seizure Safety Checklist available in Ireland through the epilepsy.ie website. The tool is used by clinicians to support discussions about risk with people with epilepsy. Supported by the fundraising efforts of the Corrigan family, who organized the 'Cycle For Shane' fundraising event in 2022, and initially planned to launch in 2023, this is now one of our main objectives for 2024.

Supporting SUDEP research has consistently been highlighted by Epilepsy Ireland members and service users as a key priority for our research investments. Dr Yvonne Langan (St James's Hospital/ Trinity College) continues to lead a project in conjunction with the HRB to establish the incidence of SUDEP in Ireland using the HRB's existing National Drug-Related Deaths Index (NDRDI) data collection infrastructure interrogating coroners' records. When completed, this will be the first national examination of SUDEP incidence in Ireland, and preliminary data was presented at the International Epilepsy Congress in Dublin in September. Full publication is expected in 2024, and we hope this will add further weight to the need for a national multi-stakeholder SUDEP-prevention strategy.

Advocacy, Campaigns and Communications

Strategic Aim 4:

Transform perceptions of epilepsy and public policy relevant to the condition.

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

We aim to transform perceptions of epilepsy through awareness-raising campaigns and through specific advocacy campaigns that positively impact on the lives of people living with epilepsy.

International Epilepsy Day, held annually in February, is our main public awareness opportunity. In 2023, we aimed to build on previous work highlighting the key seizure first-aid words of “Time, Safe, Stay” using a variety of paid and organic approaches. The theme chosen was to make seizure first-aid and the three key words ‘general knowledge’. Some of the highlights included:

- Audio adverts were run on Today FM & Spotify.
- Visuals were carried in the Irish Times and Irish Independent.
- The key message and personal stories were covered across the media including the Irish Examiner, the Irish Farmer’s Journal, Her.ie, Joe.ie, Virgin Media news and several regional radio stations and newspapers.
- Vox pop video ‘general knowledge’ interviews with members of the public were used for online engagement.
- Paid social media channel advertising generated a total of 2.5 million impressions.

As always, our media volunteers were critical to the campaign in 2023, sharing their lived experience of epilepsy and helping to spread the word on the day. Thank you to everyone who helped increase knowledge of “Time, Safe, Stay” on #EpilepsyDay.

In September, we had the opportunity to conduct a new public awareness campaign, again promoting greater understanding of seizure first aid. Asking the question “If I fall down, will you stand up?”, the eye-catching outdoor campaign featured two Epilepsy Ireland volunteers, Paul and Lucy, and encouraged everyone to visit our website to learn more about how to correctly respond to a seizure.

The campaign was featured in locations across Dublin and kindly supported by the National Transport Authority of Ireland (NTA), helping us reach a large group of people with this important message. Thank you to the NTA, our incredible volunteers, and to Connelly Partners who put together the campaign and secured placements, largely on a pro-bono basis.

Other awareness campaigns held in 2023 included:

National Epilepsy Week:

The theme of the week was #EpilepsyMatters and highlights included a Dáil debate on our Free Travel campaign; the launch of our Epilearn app; and a widely shared video raising awareness of epilepsy by our Media volunteer, Cara.

SUDEP Action Day (October):

See 3.4 above.

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Infantile Spasms Awareness Week:

2023 was our third year of taking part in Infantile Spasms Awareness Week. The week takes place internationally in December and aims to raise awareness of this rare but extremely serious seizure disorder, which if untreated, can cause significant damage to a child's developing brain. Our activities were supported by volunteers Paul and Christine, who shared their story of their son Harry's diagnosis, as well as Tina's story of her son Noel's diagnosis. Both stories helped highlight the importance of knowing the signs of Infantile Spasms and the key word of STOP, which stands for:

- See the Signs
- Take a Video
- Obtain Diagnosis
- Prioritise Treatment

2023 was a landmark year with some of our most longstanding advocacy campaigns successfully concluded. This includes the issues of deferred exams and Free Travel eligibility, as well as the establishment of an inquiry into the historical licensing and prescribing of the epilepsy drug, Sodium Valproate.

As a result of a longstanding campaign by Epilepsy Ireland, it was announced in 2023 that from July 2024, people who are medically unfit to drive for at least a year will be able to apply for the Free Travel Scheme. The barrier of having to be on a qualifying payment will be removed. The announcement came in Budget 2024 in October and followed continued advocacy by Epilepsy Ireland to TDs and Senators; the Department of Social Protection; and Minister for Social Protection, Heather Humphreys.

Throughout our engagement, the Minister showed a clear understanding of the impact that this issue can have on people with epilepsy, and a strong desire to lessen the burden. We look forward to continuing our work with the Minister and her Department to introduce these much-needed changes from mid-2024, something that will not only benefit the epilepsy community, but others who live with long-term health conditions or disabilities.

After considerable progress on the matter of deferred Leaving Cert exams in 2022, an effective solution was implemented in 2023. In the past, many students with epilepsy who experienced a seizure before or during their exam – which prevented them from completing their paper – had no other option but to repeat their exam in the following year.

As with Free Travel, Epilepsy Ireland had campaigned on this issue for many years, seeking improved accommodations for students impacted by a seizure at an inopportune moment. In 2022, deferred exams were introduced for medical conditions (including epilepsy) but only made provision for students who had a medical emergency, such as a seizure, prior to the commencement of their exam. After further efforts by Epilepsy Ireland with the State Examinations Commission and the Minister for Education, deferred eligibility was expanded from 2023 to include students who experienced medical emergencies during their exams. This was an extremely welcome development for students with epilepsy and will alleviate what for decades, was an unnecessary additional worry at one of the most stressful periods of the young person's life.

Working with our colleagues in OACS Ireland, we also secured Government approval to formally establish an inquiry into the historical licensing and prescribing of Sodium Valproate. We were delighted to receive this commitment in July after a joint campaign that lasted for over a decade.

With a Terms of Reference agreed for the inquiry and the Department of Health in the process of recruiting a chairperson at the end of 2023, Epilepsy Ireland adopted a different role in relation to work on the inquiry. The outstanding matters such as the Chair, resourcing the inquiry, and ensuring families are supported to take part

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in the inquiry effectively, are all matters that must, above all else, meet the needs of those most directly affected i.e. families who have been impacted by the drug. As those needs are directly represented by OACS Ireland, it was agreed that OACS will be leading on these final steps in 2024. We look forward to this long-awaited inquiry being officially established in 2024.

A range of other advocacy activities were undertaken in 2023, including:

- Highlighting anti-seizure medication shortages and raising concerns around the shortage of Rivotril in early 2023.
- Successfully advocating for reimbursement of new anti-seizure medication, Cenobamate, meaning it is available to patients under the Long-Term illness and General Medical Service schemes.
- Engaging with the HSE and HPRA regarding the implementation of a pregnancy prevention programme associated with Topiramate.
- Participated in the Department of Education consultation on reviewing EPSEN (Education for Persons with Special Educational Needs) Act, highlighting the educational needs of children with epilepsy.
- Working with the Neurological Alliance of Ireland regarding the implementation of the WHO Intersectoral Global Action Plan on Epilepsy and other Neurological conditions.

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

As a result of the successful outcomes to the advocacy campaigns and the public awareness initiatives discussed above in 4.1, as well as the International Epilepsy Congress, Epilepsy Ireland maintained a strong public profile during the year, both online and in traditional media.

In 2023, our epilepsy.ie website had just under 180k visits, showing its importance to the epilepsy community in finding information and support. Several new sections were added to the site, including:

- Information about medication shortages and how to access reliable information on shortages.
- Information on how to report side effects from anti-seizure medications.
- New information resources on rare epilepsies.
- New section featuring personal testimonies on the lived experience of epilepsy.

Information contained on the site was reviewed in full in 2023, with amendments and updates made to existing resources. We will continue to develop and monitor the site in 2024.

Our social media channels continue to be an important aspect to our communications, in reaching the wider public and driving people to our website for further information about epilepsy and the supports we offer. Our main channels continue to be Facebook and Instagram – with nearly 24,000 followers on Facebook at the end of 2023 and nearly 6,000 followers on Instagram. We also maintained our Twitter/ X presence (5,500 followers), continued to grow our profile on LinkedIn and Tiktok, and set up a new Threads profile at the end of 2023.

In addition to the above, our normal suite of communications activities continued in 2023 including four editions of our member's newsletter, 'Epilepsy News'; our annual Research Bulletin; and our monthly e-zines.

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 funding is through seven Section 39 Service Level Agreements (SLAs) with HSE Community Healthcare Organisations (CHOs) across the country. These agreements totalling €750,148, plus one-off funding of €29,449 in 2023 (2022: €750,148) contribute to staffing and other costs related to our support and education services.

HSE funding cuts during the post-2008 recession have never been restored, which combined with increasing costs, inflation, and an increased demand for our services in the intervening years has meant that HSE funding does not cover the full cost of delivering these services. We have worked to minimise funding shortfalls over the past 15 years through cost control measures, securing funding from other sources (e.g. Scheme to Support National Organisations) and by growing non-grant sources of income.

In 2023, there was a funding shortfall of €74,020 (2022: €53,123), which has been met by utilising unrestricted income raised/ earned during the year. In 2023, the HSE provided additional one-off funding in recognition of inflationary cost increases incurred over the course of 2022, and the impact of these costs on the cost of delivering services. Amounting to €29,449, this additional funding helped to minimise the HSE-funding shortfall.

An important external development in 2023 was the agreement between the Government and trade unions to a pay increase of 8% for all Section 39 workers. Although details were not available on the implementation of the pay deal at year end, it is hoped that funds made available through the deal in 2024 will assist in retaining staff and ensuring that fair remuneration is maintained in the current economic climate. We will continue to work with other organisations and representative bodies such as the Disability Federation of Ireland to ensure that a more sustainable funding model is put in place for Section 39 organisations.

Another important source of core funding is the Scheme to Support National Organisations (SSNO). First obtained in 2019, funding was renewed by Pobal for a further three-year period from July 2022 at the increased rate of €84,993 per annum. The funding supports key roles within the organisation.

Other sources of grant income in 2023 included the RTE Toy Show Appeal (€26,000) and Mayo Sligo Leitrim ETB (€69,431) who funded the Training For Success course at ATU Sligo until its closure in August.

Total non-grant income in 2023 was €905,599 (2022: €593,597). This includes income from fundraising activities, donations, in-kind donations, training income, membership fees, interest received and other miscellaneous income.

Fundraised income has increased each year since the pandemic-affected 2020, and while it continued this trend in 2023, income from fundraising activities has yet to fully return to pre-pandemic levels.

Nonetheless, fundraising performance was strong in 2023, especially considering that two of the four fundraising posts (including the role of Fundraising & Development Manager) were unfilled for the first half of the year.

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Income from collections and donations (including donations in-kind) increased in 2023, and the receipt of unexpected legacy income totalling €204,471 was the main reason for the increase in overall non-grant income. Income from fundraising events including marathons & challenges and Purple Day® exceeded expectations, although some events performed poorly – most notably the long-running Rose Week appeal which was cancelled in 2023. Other income-generating activities including the Time For A Break monthly draw, the annual members' raffle, and membership were in line with expectations. Corporate support in 2023 included Neuraxpharm (€10,000), Integer (€20,000), Nephin Energy Ltd (€10,000) and Connelly Partners (donation in kind of €45,237). In addition, Desitin Pharma (€10,000) agreed to support the 2024 International Epilepsy Day campaign, while Angelini Ltd agreed to support the creation of a new Youth Resource Officer role from Q2 2024. The role will build on our ongoing work with teens and young adults and expand our services for this important group.

Although the latter is not recognised as income in our 2023 financial statements, these welcome supports will help meet our strategic goal of diversifying our income base in the coming years. The appointment of a new Fundraising & Development Manager in mid-2023 will be another important factor in developing and implementing a sustainable fundraising strategy over the remainder of the current strategic plan.

Income from our training programme in epilepsy awareness and the administration of Buccal Midazolam (See 3.2 above) is another vital source of unrestricted funds for the organisation and in 2023, this amounted to €199,730. This represents a significant increase on the previous period (2022: €166,792), in part due to a small fee increase for the service, the first since 2009, and in part due to additional capacity created in the final quarter to meet the sustained demand.

As in previous years, we had incredible support from the epilepsy community and public with our fundraising efforts. We are reliant on the generous support of thousands of people across the country who contribute their time, expertise and passion every year to volunteer and fundraise in many different ways, and we thank everyone who supported our work during 2023. There are unfortunately too many people to note individually here, but some of the most memorable volunteering efforts included:

- Mark McGuire from Co. Kildare who climbed Kilimanjaro, raising €8,271.
- The Glennon family who came together to take part in the VHI Women's Mini-Marathon, raising €5,430.
- Sharon Gilligan from Co. Galway who ran the Dublin Marathon and raised €13,114.
- Tom Carroll & Friends who cycled from Mizen to Malin and raised €3,792.
- Rhona McCarton from Co. Dublin who hosted a coffee morning and raised €3,475.
- Rachel Carway and her new husband Padraig, who used their wedding day to raise funds for EI in memory of the late Brianna Lynch.

Without the support of people like Mark, Sharon, Tom, Rhona, Rachel, the Glennons and many, many others, the work outlined in this report would not have been possible – thank you to one and all for your support.

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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 the highest standards of corporate governance and understand that this is a key enabler in delivering on 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 the Triple Lock means that we:

- Have fully implemented the Charities Regulator Charities Governance Code.
- Maintain compliance with the Guidelines for Charitable Organisations on Fundraising from the Public.
- Prepare our annual financial statements in compliance 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. We annually complete the Charities Governance Code Compliance Record Form, and this was reviewed and approved by the Board in July 2023.

We have also maintained an additional non-profit-specific quality standard since 2015. We were accredited under the PQASSO/ Trusted Charity standard from 2015 to 2021. In 2021, we were accredited under the Improving Quality (IQ) system at Foundation level. IQ is a UK-based standard developed for smaller non-profit organisations, assessing the organisation's governance and management under the indicators of accountability, welcoming, effectiveness and sustainability. We plan to renew the IQ accreditation in 2024.

The Board regularly reviews the organisation's operational and governance policies in accordance with a schedule agreed in 2021. Key policies are reviewed annually, and all policies are reviewed once every three years. Those reviewed annually include financial controls & procedures, risk management and directors' interests.

Activities of the Board of Directors 2023

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

Seven board meetings were held in 2023 (2022: eight). Six meetings were held remotely, and one was held in-person. During the year, the board:

- Monitored progress at each meeting against the agreed 2023 operational plan and budget.
- Reviewed and reconfirmed the organisation's full compliance with the Charities Regulator Governance Code.
- Reviewed and agreed the organisation's risk register twice during the year and approved actions to mitigate identified risks.
- Reviewed and approved updates to almost 20 operational and governance policies & procedures per the agreed review schedule.
- Reviewed and agreed changes and movements in the organisation's designated reserves (see Reserves & Investments section below).

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- Reviewed and approved proposals on staff salaries, with reference to available benchmarking data and available resources.
- Undertook an analysis of potential long-term cost-reduction measures and agreed follow-up actions.
- Reviewed and agreed decision on the effective use of the organisation's deposits.
- Conducted a review of the organisation's insurance policies.
- Agreed an update to the Board development plan.
- Established a new Research sub-committee of the board and agreed to review all subcommittees and their composition in early 2024.
- Agreed to discontinue the Training For Success programme at ATU Sligo from August 2023.
- Approved the recruitment of two new staff roles in 2024 within services and communications/advocacy.
- Recruited five new directors and undertook recruitment towards year-end for the finance and audit sub-committee.
- Received departmental updates from management team in the areas of support services, training, fundraising and advocacy/communications.
- Undertook a governance training day, covering aspects like board effectiveness, board development, risk management, board and director responsibilities, communication and stakeholder management.
- Approved an operational plan and budget for 2024.

6.2 Strengthen our organisational structure and capacity.

Whereas 2022 had been a challenging year in terms of retention and recruitment of staff, stability returned in 2023. Two vacancies in the fundraising team, including the role of Fundraising & Development Manager were filled. The closure of Training For Success enabled the redeployment of a staff member elsewhere in our training department, and one Community Resource Officer vacancy was filled.

In late 2023, funding was secured to recruit a new Youth Resource Officer, an initiative prioritised in our 2022-2026 Strategic Plan. The role will see the development of a new Young Epilepsy Programme, involving the design, delivery and evaluation of programmes and resources for children and young people with epilepsy, as well as their families and carers, and health/education professionals. The role will be recruited in 2024.

In addition, the Board agreed to the recruitment of a new post to enhance the communications and research capacity of the organisation. Recruitment will take place in 2024, funded through the organisation's Strategic Plan designated reserve.

A review of staff salaries was undertaken during the year, using available data to benchmark against other similar organisations and the wider non-profit sector. Having considered a range of internal and external factors, the Board agreed to a 1.5% general increase in salaries, effective from July 1st 2023. In the absence of increased HSE funding for Section 39 organisations like Epilepsy Ireland for well over a decade, this increase is funded through unrestricted funds. It enables the organisation to address retention issues, remain competitive and reward strong performance, while ensuring that the financial stability of the organisation is maintained.

Five new board members were appointed in 2023, prioritising identified gaps in the board's collective skills and experiences, including legal, HR, financial and communications. Three of the five appointees have a direct connection to epilepsy (i.e. either are persons with epilepsy or a family member of a person with epilepsy). A new research sub-committee was set up during the year to advise the board on research investments and related matters, and the board also agreed to undertake a full review of its sub-committee structure in early 2024. The Board also participated in a bespoke governance training workshop during the year, designed to

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improve further the board's effectiveness, and agreed to an externally-led board evaluation review for early 2024.

6.3 Invest in our technology needs.

Work continued in 2023 on further developing the CHAMP CRM system for fundraising and membership management. The system began to manage other aspects of our work, including our training programmes. In addition, a significant upgrade of our network and IT infrastructure was completed.

The EpiLearn e-learning app was also launched in 2023, adding a new digital, interactive educational resource to our portfolio for anyone seeking to learn more about epilepsy.

The new app contains structured pathways of learning and features videos, quizzes, and practical exercises. The app was launched with one initial pathway, designed to give users an introduction to epilepsy, but there is considerable scope to develop the service further in the coming years.

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 Epilepsy Ireland board of directors is responsible for setting the direction and strategy of the organisation and for ensuring that it is effectively and responsibly governed.

As of 31 December 2023, the board is comprised of 14 volunteer members, drawn from a variety of backgrounds, skillsets and experiences. In recent years, the board has focused on achieving greater balance in terms of expertise, association with epilepsy, and demographic factors such as age, geography, gender and ethnicity.

Some of these initiatives have been successfully implemented e.g. age and skills diversity, but the board acknowledges that further progress is needed in other areas including ethnic diversity and additional regional representation on the board. Eight board members have a direct personal connection to epilepsy (i.e., either they or a close family member lives with the condition), three are medical/ scientific professionals and three provide specialist skills and knowledge required by the board.

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Operations of the Board

The board governs the organisation in accordance with its constitution, and within an agreed governance framework. This includes role specifications for board members and officers; terms of reference for sub-committees; a schedule of matters reserved for the board; and an agreed division of responsibilities between the CEO and Chairperson. It also operates under a range of policies and procedures including on confidentiality; conduct; and conflicts of interest.

It is acknowledged that conflicts of interest will arise from time to time and the Conflict of Interest policy outlines how the board will effectively identify, record and manage conflicts of interest when they arise. A register of interests is maintained and reviewed annually. In addition, at the start of every board meeting, there is an agenda item addressing potential conflicts of interest with respect to items scheduled for discussion and decision at that meeting.

Recruitment & appointment of directors

The organisation's Constitution specifies that directors may ordinarily serve up to two four-year terms (from the date of adoption in 2017). The Constitution also sets out the minimum (5) and maximum (20) number of directors; stipulates that a minimum of 25% of the board must have a direct connection to epilepsy; and sets rules for the appointment (including co-option) and removal of directors.

Board recruitment and development is overseen by the Governance & Nominations sub-committee, which manages recruitment processes, reviews applications, interviews and vets candidates and makes recommendations to the board on appointments. Recruitment strategies in recent years have included seeking nominations from Epilepsy Ireland members, approaching existing volunteers and availing of the services of Boardmatch.

An induction process is in place for newly appointed directors who are provided with a detailed information pack on the organisation's work, policies & procedures, finances, governance structures, recent board packs etc. The pack is reviewed in one or more induction meetings with the CEO prior to the new director's first board meeting.

Five new directors were appointed to the Board in 2023. Nicola Saarsteiner and Mark Curran, both qualified barristers, were co-opted to the board in February and elected to a four-year term at the AGM in June. These appointments addressed the legal expertise gap in the board's collective skillset. In October, Anne Maguire, Nicola Nagle and Aaron Chalke were co-opted to the board, adding invaluable skills in research, finance and communications. Three of the five appointees have a direct personal connection to epilepsy.

Three directors – Mark Dowdall, Derry Gray and Shane O'Brien - resigned from the Board during the year. Mark had served on the board for many years, including six years as Chairperson from 2013-2019. Derry stood down after eight years as a director, while Shane decided to step down for employment reasons. We thank all three for their many years of service and commitment to the epilepsy cause and we wish them well in their future endeavours.

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Board composition.

As at 31st December 2023, the Epilepsy Ireland board members were:

Cathy Grieve (Chairperson)

Cathy has had epilepsy since 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 with BBC News, she set up her own media production company in 2009.

Clare O'Dea (Company Secretary)

Clare joined the Board of Epilepsy Ireland in 2017. Her interest in the work of Epilepsy Ireland emerged when her son was diagnosed with a rare form of epilepsy. She brings a wealth of experience gained in corporate strategy, finance, investments, marketing and fundraising. She holds an MBA from the UCD Smurfit Graduate Business School and a Higher Diploma in Psychology from UCD.

Paul Kehoe (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. 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, 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 also produces films and is currently studying for a postgraduate diploma in Advanced Producing for Film and TV in TUD with Screen Ireland. 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).

Mary Fitzsimons

Mary is a former funded Investigator with the FutureNeuro centre at RCSI. Now retired, she was previously Principal Physicist at the Department of Neurophysics at Beaumont Hospital, where she was responsible for the development of the Epilepsy Electronic Patient Record. She has a long history in the field of epilepsy

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research and service development and joined the Board in 2018.

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 well as 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.

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Board Meeting attendance 2023

	Feb	Mar	May	July	Sept	Oct	Dec	Total
Cathy Grieve	Y	Y	Y	Y	Y	N	Y	6/7
Clare O'Dea	Y	Y	Y	N	Y	Y	Y	6/7
Paul Kehoe	N	Y	Y	N	N	Y	Y	4/7
Mary Fitzsimons	N	Y	N	N	Y	Y	Y	4/7
Ambrose Kealy	Y	Y	N	Y	N	Y	Y	5/7
Paul Fahey	Y	Y	Y	Y	N	Y	Y	6/7
Mary King	Y	Y	Y	Y	N	N	Y	5/7
Anne Kilroy	Y	Y	Y	Y	Y	Y	N	6/7
Helen Behan	Y	Y	N	Y	Y	Y	Y	6/7
Derry Gray	N	Y	Y					2/3
Shane O'Brien	Y	Y	Y					3/3
Mark Dowdall	Y	Y	Y					3/3
Nicola Saarsteiner		Y	Y	N	N	Y	Y	4/6
Mark Curran		Y	Y	Y	Y	Y	Y	6/6
Aaron Chalke							Y	1/1
Nicola Nagle							Y	1/1
Anne Maguire							Y	1/1

Y	Present
N	Apologies
	Not a director

Role and activities of sub-committees

The board has established sub-committees which considers and makes recommendations to the board on matters specified in their terms of reference. These are:

Finance & Audit sub-committee:

The Finance & Audit sub-committee assists and advises the Board on the organisation's finances, risk, investments & reserves, general business activities and strategic direction. It consists of a mixture of board members and independent external experts. In 2023, the committee met on seven occasions. It made recommendations on annual budgeting, risk management, financial controls, pay policy, cost reduction measures, epilepsy research investments and the use of reserves and deposits. It also received updates on fundraising and funding activities throughout the year. Three members stepped down during the year and the Board thanks Shane O'Brien, Tony Rhatigan and Derek Heffernan for their contributions. At year end, a recruitment process was underway to fill the vacant roles.

Governance & Nominations sub-committee:

The Governance & Nominations sub-committee advises the Board on all matters of governance including on the composition of the board, board development and recruitment. It met three times in 2023, focusing on board and sub-committee recruitment, actions arising from governance training undertaken, board skills analysis, recommending a board development plan to the board, and monitoring the updating of internal policies & procedures.

Quality & Safety sub-committee:

The Quality & Safety sub-committee oversees matters of quality, safety and risk management in our services and across the organisation. It met twice in 2023, focusing on reviewing the organisation's risk register and risk management policy, health and safety matters, complaints, and reviewing the organisation's seizure management policy.

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Remuneration sub-committee:

The sub-committee sets the CEO's objectives, appraises the CEO and reports to the Board on the CEO's performance. The sub-committee did not meet in 2023. The sub-committee is also responsible for setting the CEO's remuneration. The CEO's remuneration was set in 2016, and all subsequent general salary increases approved by the board have not been applied to the role.

Business Development & Sustainability sub-committee:

The sub-committee assists, supports and advises the Board in ensuring that the organisation's income generation activities are sufficient to meet the financial, strategic and operational needs of the organisation into the future. The sub-committee did not meet in 2023.

Research sub-committee:

This new 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 met once in 2023 to review funding applications received under the Irish Research Council's Enterprise Partnership Scheme, and to make funding recommendations to the board.

Due to several changes to board composition during the year, the composition and schedule of sub-committees was also affected. In quarter 4, following the recruitment of new board members, the Board took steps to reconstitute the sub-committees and to review the status and role of the sub-committees. This work was completed in early 2024.

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.

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FINANCIAL REVIEW

<u>Results for the Financial Year</u>	2023	2022
	€	€
Net income/(expenditure) for the financial year	146,226	(108,093)

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

Epilepsy Ireland recorded a surplus of €146,226 in 2023, a significantly improved result compared to 2022 (deficit of €108,093), and also significantly better than had been projected in the 2023 budget.

This is the first surplus recorded since 2020 and is mainly as a result of unexpected income from legacies during the year totalling €204,471. However, several other fundraising activities, including funds raised through supporter events and challenges, collections and non-government grants also performed better than in 2022 and ahead of 2023 expectations. Additional one-off HSE funding to address rising costs of providing services and increased income from training services were also important factors in ensuring that income increased by over €339,000 compared to 2022.

Although overall expenditure increased to €1.722m (2022: €1.638m), this too was within budget and is the result of an ongoing close focus on managing costs across our work in programmes, fundraising, administration, compliance and strategic projects. Staff costs were broadly similar to the previous year and to budget. In addition, a small number of planned projects and research investments did not materialise during the year as initially planned.

Reserves and Investments

Total reserves at the end of 2023 are €1,609,724 an increase from €1,463,498 at the end of 2022. Reserves consist of restricted funds of €125,107, designated funds of €500,000 and an unrestricted operational reserve of €984,617.

Restricted reserves include amounts relating to HSE (including National Lottery), the RTE Toy Show Appeal and a number of other grants which are to be applied for grant-agreed purposes in future periods. Restricted amounts also include funds raised by the Young family (€80,894) in 2021, 2022 and 2023 which are to be used for the establishment of an expanded 'aids & appliances' scheme. Other grants include a restricted grant €9,327 for the Aids and Appliances scheme received from Edwards Lifesciences in 2022.

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

The most recent review of designated reserves by the board was in 2023, which examined the appropriateness of the designations and the amounts designated. The following changes were approved by the board:

- Increase the Research designated reserve to €150,000 to cover current and future investments in medical research.
- Increase the Awareness Campaigns designated reserve to €100,000 to fund International Epilepsy Day campaigns for the remaining years of the current strategic plan.

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- Undesignate €50,000 held as a designated reserve for Aids & Appliances provision and merge this into the Strategic Plan designated reserve.
- Retain €100,000 in the Premises designated reserve.

It was also agreed to utilise funds from the Strategic Plan reserve to support the new role of Communications and Research Executive, to be recruited in 2024. Funds will support the role for two years, and during this period, efforts will be made to obtain external funding to sustain the role into the future.

At the end of 2023, unrestricted operational reserves were €984,617 (2022: €942,000). Per our reserves policy, also updated in 2023, 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 stipulates that the organisation holds at least six months of operational expenditure to ensure continued financial security and to provide for contingencies. In addition, the policy states that the total amount held across the unrestricted operational reserve and combined designated funds should be at least €1 million. The reserves position at the end of 2023 met these stipulations.

The organisation's investment policy details our approach to investing/ depositing available funds. The primary objectives outlined in the policy are to:

- Provide a stable source of liquidity and financial support to achieve our mission into the future.
- Attempt to maintain the purchasing power of the reserves in real terms.
- Maintain a low risk profile.

The policy details targets for liquidity, short term deposits (≤ 3 years) and medium-term deposits (3-5 years). These are detailed in the table below along with the current position as at 31st December 2023, following a review of maturing deposits by the board during the year.

	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	€371,218	€1,111,753	€0

Liquid funds consist of current accounts held at Bank of Ireland and AIB. Short term deposits consist of term deposit accounts held at Bank of Ireland, Permanent TSB and in State Savings Bonds.

Risks and uncertainties

The Board has approved a risk management policy for the organisation and maintains a risk register detailing all organisational risks, the mitigation measures in place and actions needed to minimise these risks. The register is reviewed twice annually by the Board and by the Finance & Audit and Quality & Safety sub-committees. Risks are analysed under human resources, information technology, fundraising, finance, services, governance, strategic and other. Risks are rated on an inherent and residual basis as high, medium or low risks based on the likelihood of occurrence and potential impact.

The following are the most significant risks faced by the organisation, as outlined in the most recent review of the register by the Board (February 2024), along with a summary of mitigation actions:

Insufficient capacity to meet: changes in service demand; compliance requirements; stakeholder expectations; or strategic plan aims.

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Actions: Seek out funds to develop volunteer programme envisaged in strategic plan; operate the newly launched service user consultation group and undertake service user satisfaction/ feedback surveys; conduct a midpoint review of strategic plan in 2024; identify funding opportunities to enable further expansion of staffing resources in target areas.

Drop in Fundraising Income/ Poorly performing fundraising activities.

Actions: Review role and composition of Business Development & Sustainability sub-committee; develop income generation plan in line with Strategic Plan; close monitoring of fundraising activities and data including those which may be under-performing; develop fundraising assets including a new case for support; rollout of new online fundraising plans; further agreed investment in fundraising budget; monitor impact of increased investment and determine future fundraising infrastructure needs (including staffing).

Inadequate HSE funding; Overdependence on HSE income

Actions: Develop income generation plan in line with strategic plan including case for support; meet income generation targets in 2024 budget; ongoing advocacy and engagement with sectoral efforts to increase Section 39 funding; monitor and apply for new funding opportunities including via HSE business cases; review fundraising staffing needs.

Relationship with key funders

The risk rating was elevated to reflect potential changes to how Section 39 organisations may be funded in future, in particular, the possibility of smaller organisations being funded via grant aid agreements rather than service level agreements. The full implications of such a change, which is currently being piloted by HSE, are not currently fully understood. This risk rating also reflects the growing volume and complexity of reporting and compliance obligations associated with various funding arrangements in recent years. We will engage with HSE and sectoral representative bodies on these issues throughout 2024.

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 are regularly monitored and policy is adhered to.

Several risk ratings were lowered in 2023 including those relating to IT infrastructure (investment made to upgrade); board expertise and composition (five new directors appointed with mix of skills); and the risk of discontinuing services (following eventual closure of TFS). Increased risk ratings were applied to the cost of fundraising.

Overall, financial risks continue to be the highest priority. The Board acknowledges the organisation's dependence on HSE Section 39 funding to continue providing core services. It also acknowledges that the organisation needs to generate additional unrestricted income, including from fundraising, if the organisation is to meet its stated objectives. The Board remains confident that assumptions made in budgeting for 2024 are appropriate and that the organisation will be able to take steps, if required, to address emerging financial challenges e.g. utilisation of reserves/ designated funds or actions to cut costs.

Going Concern

Taking into account the analysis above of financial performance, the funding and fundraising environment, current risks and uncertainties, our current forecasts and projections, and the reserves held by the organisation, 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.

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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. Further details can be found 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. The board annually reviews and updates the organisation's detailed Financial Controls and Procedures, on the recommendation of the Finance & Audit sub-committee. The most recent review was in October 2023.

The Finance and Audit sub-committee reports directly to the board through the Treasurer and Chair 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 each sub-committee and board meeting.

FUTURE PLANS

As discussed in the Objectives & Activities section, the Board approved a five-year strategic plan in 2022 setting the direction and objectives of the organisation for the period 2022-2026.

Our plans for the next three years (to end 2026) in each of the six strategic aims, as outlined in the plan, can be summarised as follows:

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 who have traditionally been the driving force behind many aspects of our work, we will increase the number of volunteers engaged with us 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 develop collaborative models of service that promote 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

DIRECTORS' REPORT

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 expanding 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.

Short-term future plans

The Board will undertake a mid-point review of the Strategic Plan and progress made to date during 2024. This will be an opportunity to ensure that the stated aims and objectives remain relevant, reassess the environment the organisation operates in and make modifications to the plan as appropriate.

The Board annually approves an Operational Plan and budget based on the Strategic Plan, containing specific goals and tasks for the year ahead. Progress reports against the Operational plan and budget are monitored and discussed at each board meeting. Actions in the 2024 Operational Plan include:

- Provide one-to-one support services to >7,500 individual contacts.
- Complete the development of resource pack on epilepsy for healthcare professionals.
- Recruit Youth Resource Officer and develop/ roll out Young Epilepsy Programme.
- Continue programmes including Teen Time, Get ChARTy, Monthly Meet Ups, Living Well With Epilepsy, Joint EI/HSE workshops for newly diagnosed patients and STEPS.
- Launch expanded aids & appliances scheme.
- Launch the epilepsy consultation checklist & training resource for GPs in collaboration with UCC.
- Facilitate service-user consultation group.
- Provide face-to-face and online training for 2,500 professionals in epilepsy awareness and the

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administration of midazolam.

- Support and collaborate on new and existing EI-funded research projects.
- Launch SUDEP Incidence Study including publication and media event. Progress campaign for development of a national SUDEP Strategy.
- Launch SUDEP & Risk checklist in Ireland in collaboration with SUDEP Action.
- Organise and deliver awareness programmes including the #EpilepsyDay campaign in February.
- Conduct service user survey on advocacy priorities and agree new advocacy agenda.
- Increase fundraised income, develop suite of new fundraising assets and case for support.
- Establish new board subcommittee focused on communications and fundraising.
- Review and update Governance Code compliance records & maintain Triple Lock.
- Achieve recertification of Improving Quality standard.
- Conduct an assessment of EI's Constitution.
- Conduct review of premises requirements.

DIRECTORS AND SECRETARY

A list of current directors is shown on page 2. The directors, and secretary, who served at any time during the financial year except as noted, were as follows:

Directors:

Ms C. Grieve (Chairperson)

Ms H Behan

Mr A. Chalke (appointed 24th October 2023)

Mr M. Curran (appointed 7th February 2023)

Mr M. Dowdall (resigned 23rd May 2023)

Mr P. Fahey

Ms M. Fitzsimons

Mr D. Gray (resigned 23rd May 2023)

Mr A. Kealy

Mr P. Kehoe

Ms A. Kilroy

Prof M. King

Ms A. Maguire (appointed 24th October 2023)

Ms N. Nagle (appointed 24th October 2023)

Mr S. O'Brien (resigned 23rd May 2023)

Ms C. O'Dea

Ms N. Saarsteiner (appointed 7th February 2023)

Secretary:

Ms C. O'Dea

POST BALANCE SHEET EVENTS

There have been no other significant events affecting the company since the financial year end other than what is disclosed on Note 27.

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DIRECTORS' REPORT

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

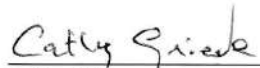
In the case of each of the persons who are directors at the time the directors' report and financial statements are approved:

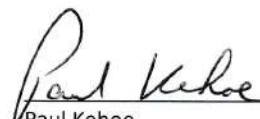
- A) So far as the director is aware, there is no relevant audit information of which the company's auditors are unaware; and
- B) Each director has taken all steps that ought to have been taken by the director in order to make himself/herself aware of any relevant audit information and to establish that the company's auditors are aware of that information.

AUDITORS

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

Approved by the Board and signed on its behalf by:


Cathy Grieve
Director


Paul Kehoe
Director

Date: 21st May 2024

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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.

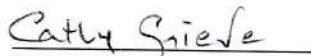
In preparing those financial statements, the directors are required to:

- 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:



Cathy Grieve
Director



Paul Kehoe
Director

Date: 21st May 2024

**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 2023, 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 2023, 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 35, 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.

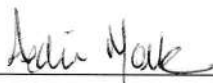
Auditor's responsibilities for the audit of the financial statements

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
for and on behalf of Mazars
Chartered Accountants & Statutory Audit Firm
Harcourt Centre, Block 3
Harcourt Road
Dublin 2
Date: 23 May 2024

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

	Note	Restricted Funds 2023 €	Unrestricted Funds 2023 €	Total Funds 2023 €	Restricted Funds 2022 €	Unrestricted Funds 2022 €	Total Funds 2022 €
INCOME FROM:							
Donations and Legacies	4	81,532	450,191	531,723	23,439	200,509	223,948
Charitable Activities	5	963,021	207,245	1,170,266	935,529	174,196	1,109,725
Other Trading Activities	6	38,505	100,904	139,409	32,858	138,892	171,750
Interest Income	7	-	4,271	4,271	-	2,375	2,375
Other Income	8	-	22,950	22,950	-	22,242	22,242
Total		1,083,058	785,561	1,868,619	991,826	538,214	1,530,040
EXPENDITURE ON:							
Charitable activities	9(a)	1,131,845	351,242	1,483,087	1,065,234	360,954	1,426,188
Raising funds	10	14,261	225,045	239,306	25,274	186,671	211,945
Total		1,146,106	576,287	1,722,393	1,090,508	547,625	1,638,133
NET (EXPENDITURE)/ INCOME							
NET (EXPENDITURE)/ INCOME	13	(63,048)	209,274	146,226	(98,682)	(9,411)	(108,093)
Taxation	11	-	-	-	-	-	-
Transfer between funds	21	101,750	(101,750)	-	80,905	(80,905)	-
Net movement in funds for financial year	21	38,702	107,524	146,226	(17,777)	(90,316)	(108,093)
Total funds brought forward	21	86,405	1,377,093	1,463,498	104,182	1,467,409	1,571,591
Total funds carried forward	21	125,107	1,484,617	1,609,724	86,405	1,377,093	1,463,498

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 42 to 58 form part of these financial statements.

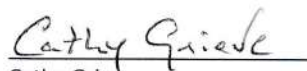
**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**


**BALANCE SHEET
AS AT 31 DECEMBER 2023**

	<i>Note</i>	2023	2022
		€	€
Fixed Assets			
Tangible assets	14	<u>122,546</u>	139,666
Current Assets			
Short-term investments	15	1,111,753	360,000
Debtors	16	246,867	149,693
Cash at bank and in hand	17	<u>371,215</u>	1,001,805
		1,729,835	1,511,498
Current Liabilities			
Creditors: Amounts falling due within one year	18	<u>(242,657)</u>	(187,666)
Net Current Assets		1,487,178	1,323,832
TOTAL NET ASSETS		<u>1,609,724</u>	<u>1,463,498</u>
FUNDS OF THE CHARITY:			
Restricted funds	21	125,107	86,405
Unrestricted funds			
- Operational Reserve	21	984,617	942,000
- Designated funds	21	500,000	435,093
TOTAL FUNDS		<u>1,609,724</u>	<u>1,463,498</u>

The notes on pages 42 to 58 form part of these financial statements.

The financial statements were approved and authorised for issue by the Board of Directors on the 21st May 2024 and signed on its behalf by:


Cathy Grieve
Director


Paul Kehoe
Director

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**STATEMENT OF CASH FLOWS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

RECONCILIATION OF NET INCOME/(EXPENDITURE) TO CASH USED IN CHARITABLE ACTIVITIES

	<i>Note</i>	2023	2022
		€	€
Net income (expenditure) for the year		146,226	(108,093)
<i>Adjustments for:</i>			
Depreciation	14	29,804	29,199
Increase in debtors		(97,174)	(20,289)
Increase in creditors		54,993	36,018
Net cash flows from operating activities		<u>133,848</u>	<u>(63,165)</u>
Cash flows from investing activities			
Purchase of tangible assets	14	(12,685)	(19,844)
Purchase of short-term investments		(751,753)	(360,000)
Cash used in investing activities		<u>(764,438)</u>	<u>(379,844)</u>
Change in cash at bank and in hand during the year		(630,590)	(443,009)
Cash at bank or in hand at the beginning of the year		1,001,805	1,444,814
Cash and cash equivalents at end of year		<u>371,215</u>	<u>1,001,805</u>
Reconciliation to cash at bank and in hand:			
Cash at bank and in hand		371,215	1,001,805

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

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 34. 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

Public donations and similar income arising from fundraising events are accounted for when received. 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.

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 2023.

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

4. DONATIONS AND LEGACIES

	Restricted funds	Unrestricted funds	Total 2023	Total 2022
	€	€	€	€
Collections	-	111,205	111,205	64,758
Donations	36,095	130,811	166,906	127,465
Donations In Kind	45,437	-	45,437	12,520
Memberships	-	3,704	3,704	11,450
Legacies	-	204,471	204,471	7,755
	81,532	450,191	531,723	223,948

Income received is primarily from the Republic of Ireland.

The restricted donations include a €500 donation restricted to expenditure in the West region.

An In-Memory corporate donation of €20,000 from Integer and €595 in other In-Memory donations are included in the In-Memory restricted fund balance carried forward of €80,894 (2022: €47,644). This relates to total funds raised in 2021, 2022 and 2023 specifically to launch a new service in future years to provide wearable seizure-monitoring devices to service users as detailed in note 21.

The restricted donations includes support of €5,000 from the International League Against Epilepsy towards the cost of Epilepsy Ireland's activities at the International Epilepsy Congress which took place in Dublin in September 2023.

In accordance with our policy on working with pharmaceutical & medical device industries, Epilepsy Ireland discloses all contributions from this sector. In 2023, we received the following contributions which are included in donations:

- Neuraxpharm Ireland; €10,000 towards the cost of providing our training services.
- Desitin Pharma; €10,000 unrestricted educational grant.

A non-cash in-kind donation of €45,236 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.

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

5. INCOME FROM CHARITABLE ACTIVITIES

Grant Income			Restricted funds	Unrestricted funds	Total 2023	Total 2022
Grantor	Grant Name	Purpose	€	€	€	€
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	3,000	-	3,000	-
HSE	CHO 8	Service Agreement	37,224	-	37,224	37,224
HSE	Inflation Fund	Service Agreement	29,449	-	29,449	-
Pobal	Stability Fund	Non-pay costs	-	-	-	19,253
ATU Sligo	Specialised Training	Training For Success	-	-	-	37,389
Mayo Sligo	Specialised Training	Training For Success	69,431	-	69,431	53,601
Leitrim ETB	SSNO	Salary and assoc. costs (2 positions)	84,993	-	84,993	75,037
Pobal	Fund	Service Delivery	26,000	-	26,000	-
RTE Toy Show Fund	Co. Council Grants	Purchase of equipment	-	-	-	2,101
			963,021	-	963,021	937,529
Non-Grant Income						
BM Training Programme			-	199,730	199,730	166,792
Other Income Generating Services			-	7,515	7,515	5,404
Total Non-Grant Income			-	207,245	207,245	172,196
Total Income from Charitable Activities			963,021	207,245	1,170,266	1,109,725

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 2023	Total 2022
	€	€	€	€
Raffles and Lotteries	25,850	12,855	38,705	36,126
Campaigns and Appeals	-	4,229	4,229	12,260
Fundraising Events	12,655	83,820	96,475	123,364
	38,505	100,904	139,409	171,750

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

7. INTEREST INCOME

	Restricted funds	Unrestricted funds	Total 2023	Total 2022
	€	€	€	€
Interest Income	-	4,271	4,271	2,375
	-	4,271	4,271	2,375

8. OTHER INCOME

	Restricted funds	Unrestricted funds	Total 2023	Total 2022
	€	€	€	€
Miscellaneous Income	-	22,950	22,950	22,242
	-	22,950	22,950	22,242

9(a). EXPENDITURE ON CHARITABLE ACTIVITIES

Activity	Activities Undertaken Directly €	Grant funding of activities €	Support costs (Note 9(b)) €	Total 2023 €	Total 2022 €
Information & support	133,013	-	543,716	676,729	664,712
Training & education	71,167	-	283,506	354,673	348,609
Awareness	92,400	-	144,421	236,821	201,915
Advocacy	-	-	103,586	103,586	101,407
Research	2,302	84,113	24,863	111,278	109,545
	298,883	84,113	1,100,091	1,483,087	1,426,188

Activity	Restricted funds €	Unrestricted funds €	Total 2023 €	Total 2022 €
Information & support	560,737	115,991	676,728	664,712
Training & education	288,007	66,666	354,673	348,609
Awareness	171,086	65,735	236,821	201,915
Advocacy	80,826	22,760	103,586	101,407
Research	31,189	80,090	111,279	109,545
	1,131,845	351,242	1,483,087	1,426,188

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

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

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

Charitable activities

Charge for financial year	€	€	Basis of allocations
Governance costs	36,290	40,893	No. Activities
Payroll Administration	881,266	865,715	Direct costs
Information Technology	19,611	13,422	No. Activities
Travel & Subsistence	21,229	13,778	Direct costs
Recruitment/Training and other costs	10,736	24,126	Direct costs
Rent and Building management services	66,274	62,144	Direct costs
Office Expenses	34,881	33,852	Direct costs
Depreciation	29,804	29,199	Direct costs
	1,100,091	1,083,129	

10(a). EXPENDITURE ON RAISING FUNDS

	Activities Undertaken Directly	Support costs (Note 10(b))	Total 2023	Total 2022
	€	€	€	€
Expenditure on raising funds	56,247	183,059	239,306	211,945
	56,247	183,059	239,306	211,945
	Restricted funds	Unrestricted funds	Total 2023	Total 2022
	€	€	€	€
Raising donations, legacies, corporate donations & regular giving	200	-	200	11,276
Fundraising activities – campaigns, appeals and events	13,561	42,486	56,047	32,267
Support costs (Note 10(b))	500	182,559	183,059	168,402
	14,261	225,045	239,306	211,945

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

Fundraising activities	2023	2022	Basis of allocations
Charge for financial year	€	€	
Governance costs	6,886	6,761	No. Activities
Payroll Administration	140,274	149,097	Direct cost
Information Technology	4,157	2,064	No. Activities
Travel & Subsistence	1,257	899	Direct cost
Recruitment/Training and other costs	23,859	4,908	Direct cost
Office Expenses	6,626	4,673	Direct cost
Total	183,059	168,402	

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2023**

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

	2023	2022
Average number of persons employed	22	22
Service delivery	13	12
Fundraising	3	4
Administration	3	3
Training	3	3
	<u>22</u>	<u>22</u>

The staff costs comprise:

	€	€
Information & Support	350,750	333,822
Training & Education	188,040	195,000
Awareness	93,879	91,768
Advocacy	87,093	95,570
Research	17,956	17,956
Administration	139,498	127,543
Fundraising	139,541	148,353
Other Compensation Costs	4,782	4,801
	<u>1,021,540</u>	<u>1,014,813</u>

Included in the above are costs as follows:

Employer's PRSI	<u>91,975</u>	<u>93,337</u>
Contributions to pension scheme (Note 23)	<u>52,868</u>	<u>54,539</u>

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

	2023	2022
€60,001 - €70,000	2	1
€70,001 - €80,000	-	-
€80,001 - €90,000	1	1

The total remuneration for key management personnel for the financial year amounted to €189,385 (2022: €187,597). Remuneration includes salaries, employer PRSI and pension contributions.

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

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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 €433 was paid during the financial year (2022: €58).

13. NET INCOME/(EXPENDITURE)

	2023	2022
	€	€
The net income /(expenditure) for the financial year is arrived at after charging/(crediting):		
Directors' remuneration and emoluments	-	-
Operating Lease	21,183	31,410
Depreciation	29,804	29,199
Auditors' remuneration for external audit services	18,081	17,220
Bank deposit interest	(4,271)	(2,015)

14. FIXED ASSETS

	Premises	Fixtures & Fittings	Computers & Equipment	Total
	€	€	€	€
Cost				
At 1 January 2023	122,470	63,089	121,764	307,323
Additions	-	-	12,685	12,685
At 31 December 2023	<u>122,470</u>	<u>63,089</u>	<u>134,449</u>	<u>320,008</u>
Depreciation				
At 1 January 2023	18,825	54,831	94,002	167,658
Charge for during the year	1,225	5,807	22,772	29,804
At 31 December 2023	<u>20,050</u>	<u>60,638</u>	<u>116,774</u>	<u>197,462</u>
Net book value				
At 31 December 2023	<u>102,420</u>	<u>2,451</u>	<u>17,675</u>	<u>122,546</u>
At 31 December 2022	<u>103,645</u>	<u>8,258</u>	<u>27,762</u>	<u>139,666</u>

15. SHORT-TERM INVESTMENTS

	2023	2022
	€	€
Short-term investments	1,111,753	360,000

All funds are invested in interest bearing deposits with financial institutions with a notice period greater than 3 months.

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16. DEBTORS: Amounts falling due within one year

	2023	2022
	€	€
Trade Debtors	182,430	94,562
Prepayments	36,925	29,154
Other Debtors	27,512	25,977
	<u>246,867</u>	<u>149,693</u>

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

17. CASH AT BANK AND IN HAND

	2023	2022
	€	€
Cash at bank and in hand	371,215	1,001,805
	<u>371,215</u>	<u>1,001,805</u>

18. CREDITORS: Amounts falling due within one year

	2023	2022
	€	€
Trade Creditors	24,919	72,853
Accruals	34,941	53,932
Deferred Income	157,634	40,735
PAYE/PRSI/USC/Pension	22,814	19,846
Other Creditors	2,350	300
	<u>242,657</u>	<u>187,666</u>

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

19. DEFERRED INCOME

	2023	2022
	€	€
Balance at beginning of year	40,735	41,363
Amount received during the year	157,634	40,735
Amount released to SOFA during the year	(40,735)	(41,363)
Balance at end of year	<u>157,634</u>	<u>40,735</u>

Total deferred income of €157,634 includes €109,892 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 €40,333 relates to HSE CHO7 income relating to 2024 which was invoiced in 2023. It also includes membership fees received of €7,409 relating to 2nd and 3rd year of membership (based on estimate, assuming the membership income received has average terms of 3 years).

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20. FINANCIAL INSTRUMENTS

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

	2023	2022
	€	€
Financial assets		
<i>Measured at undiscounted amounts receivable</i>		
· Debtors (Note 16)	<u>246,867</u>	<u>149,693</u>
Financial liabilities		
<i>Measured at undiscounted amount payable</i>		
· Creditors (excluding deferred income and PAYE/PRSI/USC pension) (Note 18)	<u>55,502</u>	<u>127,085</u>

21. ANALYSIS OF FUNDS

	Opening Balance 1 January 2023	Income	Expenditure	Transfers	Closing Balance 31 December 2023
€	€	€	€	€	€
Restricted Funds					
Health Service Executive	9,875	782,597	(856,617)	74,020	9,875
Community Foundation	4,051	-	(4,051)	-	-
SSNO Funding (Pobal)	-	84,993	(84,993)	-	-
MSLETB	-	69,431	(97,161)	27,730	-
Toyshow Appeal Funding	-	26,000	(12,989)	-	13,011
Donated Services	-	45,437	(45,437)	-	-
Restricted Donations	-	5,500	(5,500)	-	-
Other Grants	24,835	10,000	(13,508)	-	21,327
In Memory Fundraising	47,644	33,250	-	-	80,894
Research funding scheme	-	25,850	(25,850)	-	-
	<u>86,405</u>	<u>1,083,058</u>	<u>(1,146,106)</u>	<u>101,750</u>	<u>125,107</u>

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21. ANALYSIS OF FUNDS (continued)

	Opening Balance 1 January 2023	Income	Expenditure	Transfers	Closing Balance 31 December 2023
Unrestricted funds					
Operational Reserve	942,000	785,561	(470,673)	(272,271)	984,617
Designated					
<i>Premises reserve</i>	100,000	-	-	-	100,000
<i>Research Provision Awareness Campaigns</i>	114,611	-	(72,324)	107,713	150,000
<i>Aids and Appliances Strategic Plan Implementation</i>	70,482	-	(33,290)	62,808	100,000
	50,000	-	-	(50,000)	-
	100,000	-	-	50,000	150,000
	435,093	-	(105,614)	170,521	500,000
Total Unrestricted Funds	1,377,093	785,561	(576,287)	(101,750)	1,484,617
Total Funds	1,463,498	1,868,619	(1,722,393)	-	1,609,724

HSE-funded services are only partially funded and €74,020 (2022: €53,123) has been transferred from the unrestricted Operational Reserve to meet the full cost of providing the services.

€9,875 of HSE funds (2022: €9,875) is made up of National Lottery grants which are being carried forward for use in 2024.

Toy show funding Appeal funding of €13,011 to be utilised in 2024.

Other restricted grants totalling €21,327 (2022: €24,835) are also carried forward to be utilised in 2024. The In-Memory fundraising balance carried forward of €80,894 (2022: €47,644) relates to total funds raised in 2021, 2022 and 2023 specifically for the purpose of launching a new service in future years to provide wearable seizure-monitoring devices to service users.

The Board has designated reserves for utilisation in special strategic activities including undertaking epilepsy awareness campaigns; providing funding for current and future research projects; providing and sustaining an expanded Aids & Appliances scheme; 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 2023, the Research reserve was reduced by €72,324 to meet the cost of current research grants in the year. It was replenished by €107,713 to increase the designated reserve to €150,000 to meet future research investments. The Awareness reserve was reduced by €33,290, covering costs associated with the 2023 International Epilepsy Day campaign. It was also replenished

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21. ANALYSIS OF FUNDS (continued)

by €62,808 to increase the designated reserve to €100,000 for future campaigns. The Aids and Appliance reserve has been undesignated and funds moved to the Strategic Plan implementation reserve as the In- Memory restricted fund is deemed sufficient to implement current plans.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	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)
	<u>125,107</u>	<u>1,484,617</u>	<u>1,609,724</u>

In respect of prior year

	Restricted funds	Unrestricted funds	Closing Balance
	€	€	€
Fixed Assets	-	139,666	139,666
Current Assets	127,140	1,384,358	1,511,498
Liabilities	(40,735)	(146,931)	(187,666)
	<u>86,405</u>	<u>1,377,093</u>	<u>1,463,498</u>

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, €52,868 (2022: €54,539) is charged to the Statement of Financial Activities in the financial year in which it arises. There was €6,707 payable at the financial year-end (2022: €6,492).

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.

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25. COMMITMENTS

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

	2023	2022
	€	€
Within one year	75,954	111,583
Between two and five years	<u>9,000</u>	<u>62,454</u>
Total	<u>84,954</u>	<u>174,037</u>

Operating Lease Commitments

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

	2023	2022
	€	€
Within one year	22,660	28,950
Between one and two years	<u>36,605</u>	<u>25,470</u>
Total	<u>59,265</u>	<u>54,420</u>

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 €433 was paid during the financial year to directors.

27. SUBSEQUENT EVENTS

In December 2023, Epilepsy Ireland received notification for the implementation of the Workplace Relations Commissions (WRC) agreement on S39 pay.

The payments will be based on 8% of total relevant pay costs in line with the WRC agreement as per agreed implementation dates below.

- An increase of 3% from 1 April 2023
- An increase of 2% from November 2023
- An increase of 3% from 1 March 2024

In February 2024, Epilepsy Ireland received interim funding under the terms of the agreement. The level of additional funding being received is dependent on the outcome of an application process which is taking place in Q2 2024, and was not known at year end. Therefore, income has not been recognised in 2023.

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27. SUBSEQUENT EVENTS (continued)

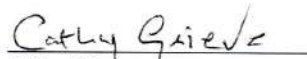
The organisation awaits the outcome of the application process in order to implement the terms of the agreement for relevant employees.


28. RECLASSIFICATION

Certain comparative amounts have been reclassified, where necessary, to ensure comparability with current financial year disclosure.

29. APPROVAL OF FINANCIAL STATEMENTS

The financial statements were approved by the Board of Directors on 21st May 2024.


Cathy Grieve
Director


Paul Kehoe
Director