

Brainwave The Irish Epilepsy Association
T/A Epilepsy Ireland

Reports and Financial Statements
for the financial year ended
31 December 2022

CONTENTS

	PAGE
DIRECTORS AND OTHER INFORMATION	2
DIRECTORS' REPORT	3 - 31
DIRECTORS' RESPONSIBILITIES STATEMENT	32
INDEPENDENT AUDITOR'S REPORT	33- 35
STATEMENT OF FINANCIAL ACTIVITIES	36
BALANCE SHEET	37
STATEMENT OF CASH FLOWS	38
NOTES TO THE FINANCIAL STATEMENTS	39-54

DIRECTORS AND COMPANY INFORMATION

DIRECTORS

Ms C. Griewer (Chairperson)
Ms R. Behan
Mr M. Curran (appointed on 7 February 2023)
Mr M. Dowdall
Mr P. Fahey
Ms M. Fitzsimons
Mr D. Gray
Mr A. Kealy
Mr P. Kehoe
Ms A. Kilroy
Prof M. King
Mr S. O'Brien
Ms C. O'Dea
Ms N. Saarsteiner (appointed on 7 February 2023)

SECRETARY AND REGISTERED OFFICE

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AUDITORS

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Chartered Accountants and Statutory Audit Firm
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BANKERS

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Bank of Ireland
Permanent TSB

SOLICITORS

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Warrington House,
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CHARITY NUMBER

CRA (Charities Regulator): 20010557
CHY (Revenue): 5170

COMPANY REGISTRATION NUMBER

17588

DIRECTORS' REPORT

The directors present their annual report and the audited financial statements of the company for the financial year ended 31 December 2022.

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

The word 'epilepsy' describes a group of disorders, all of which are characterised by recurrent unprovoked seizures involving abnormal electrical activity in the brain. It is one of the most common neurological conditions, affecting more than 40,000 people in Ireland. There are an estimated 1,300 - 2,100 new diagnoses each year. Epilepsy affects people of all ages, including an estimated 10,000 - 15,000 children. It is also more common in the elderly and in people with an intellectual disability.

Epilepsy is very much a treatable condition for the majority of people. Thanks to advances in medications and surgical techniques, up to 70% of people can become seizure-free. However, there are still up to 15,000 people living with uncontrolled seizures in Ireland today. For this group in particular, epilepsy can be a source of long-lasting, yet often hidden, disability. The condition can affect all aspects of a person's life including education, 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 and economic impact that can be associated with it. It can also have a direct and significant impact on the wider family unit.

There is also an increased risk of mortality associated with epilepsy with an estimated 130 epilepsy related deaths in Ireland each year. Deaths may result from the underlying cause of the seizures, injury/ trauma, prolonged seizures or Sudden Unexpected Death in Epilepsy (SUDEP).

The financial cost of epilepsy is also significant. In Europe, more than €15 billion is spent annually on the treatment of epilepsy, a figure comparable to that of lung and breast cancer combined. Based on recent (2022) international data, Epilepsy Ireland estimates that the total cost (direct and indirect) of epilepsy in Ireland is c. €584m per annum, equating to almost €15,000 per person.

The role of Epilepsy Ireland

Epilepsy Ireland's work is centred on reducing the burden of the condition for those living with epilepsy and their families. From our head office in Dublin and nine regional locations, we work to meet the needs of people living with epilepsy, their families and their carers through the provision of support & information services and educational & training programmes. We also work to improve public understanding of epilepsy, to advocate on behalf of the epilepsy community and to support and fund epilepsy research.

Strategic Plan 2022-2026

During 2021, the Epilepsy Ireland Board agreed to undertake a new strategic planning process to develop a new strategic plan for 2022-2026. During the term of our 2017-2021 strategic plan, demand for our services had increased; advances were made in improving public epilepsy awareness; advocacy and training activities were significantly expanded; and the milestone of investing €1m in research funding since 2010 was achieved. The last two years of the plan also saw a period of unprecedented challenges resulting from the

DIRECTORS' REPORT

COVID-19 pandemic, which influenced all aspects of our activities and fundraising

With the support of the Community Foundation for Ireland through the RTE Does Comic Relief: Adapt and Respond fund, the agency Zinto3 were chosen to facilitate the development of the new plan following a competitive process. A strategic planning working group was set up to lead the work, which began in July 2021. This involved analysing and understanding the evolving policy and funding environments within which the organisation operates, as well as recognising the opportunities and threats posed by the external environment. Central to the process was the need to fully involve key stakeholders. We undertook a highly participative process consisting of several online workshops attended by internal and external stakeholders, including those who avail of our services, staff, board, volunteers and representatives from the medical & scientific community.

These consultations shaped a plan which we believe captures the needs of people with epilepsy, their families and the wider epilepsy community. The final strategic plan, outlining a positive and ambitious, yet challenging roadmap for the next five years, was approved by the Board in April 2022.

The process included a reiteration of our existing vision; a renewed mission statement, and for the first time, defined a core set of values that our organisation holds dear and acts in accordance with.

Vision

Our vision is to achieve a society where no person's life is limited by epilepsy

New Mission Statement

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

Values

- Respect
- Empathy
- Support
- Person-Centred
- Empowerment
- Collaboration
- Trust

Six Strategic Aims

The new strategic plan is centred around six key strategic aims, which are as follows:

1. Empowering people with epilepsy through support and education
2. Centring people with epilepsy and their families in the work of Epilepsy Ireland.
3. Working collaboratively to improve the care of people with epilepsy and knowledge of the condition.
4. Transforming perceptions of epilepsy and public policy relevant to the condition
5. Increasing and diversifying our income.
6. Demonstrating the highest standards of governance and ensure the structures are in place to meet objectives.

DIRECTORS' REPORT

The Plan provides direction for sustainable development to respond to the growing needs of our community, and to deliver services that positively impact our service users. However, the Board recognises that the plan is ambitious and that there are several challenges on the road to implementation, primarily, investing in the plan with the appropriate level of resources needed. Each year, the Board will approve an operational plan and budget reflecting the aims of the new plan and will monitor progress at each board meeting.

In our Achievements & Performance section for 2022 (below), we detail the activities, challenges and achievements for 2022 under each of the organisation's six new strategic aims and the 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 central to the work of Epilepsy Ireland.

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 and 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 is supported by the Epilepsy Ireland funded Advanced Nurse Practitioner post at Beaumont Hospital.

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 general public.

2022 was another busy year for our services team, and demand remained high with the country slowly recovering from the worst effects of the COVID-19 pandemic. Several changes introduced during 2020 and 2021 such as hybrid working and the use of Zoom/Teams technologies to support service users were maintained and integrated into how we provide our services.

There was a total of 19,917 contacts with our service (2021: 22,048). 10,463 of these were one-to-one contacts via phone, email, zoom or in-person meetings (2021: 11,601), while 9,454 attended our group supports both in-person and virtual (2021: 10,477).

Included in individual contacts are 1,334 one-to-one contacts with the EI-funded Registered Advanced Nurse Practitioner (RANP) specialising in supporting women with epilepsy (2021: 1,473). The RANP provides clinics in Beaumont Hospital, the National Maternity Hospital, the Rotunda, the Conombe, and our Lady of Lourdes Hospital in Drogheda. The RANP also provides specialised epilepsy advice and support to our services team, co-

DIRECTORS' REPORT

delivers online epilepsy education sessions, participates in Epilepsy Ireland events, and contributes to the review and updating of our information materials

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. Toolkit sessions are tailored specifically to the person's needs and delivered by the local Community Resource Officer. In 2022, 365 individuals availed of the Living Well with Epilepsy Programme (2021: 234)

Our long running STEPS programme for people with epilepsy covers all aspects of epilepsy self-management and provides broader support and understanding of emotional and mental wellbeing, management of stress, positive thinking and improving confidence in managing epilepsy. Delivered in small groups, STEPs also facilitates and encourages peer learning and support. There were 20 STEPS sessions in 2022 with 76 attendances (2021: 23)

Epilepsy Ireland's support groups are another important part 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 Community Resource Officer. Local support groups continued to be run online and in-person throughout 2022 and a total of 33 group sessions were facilitated for 237 individual attendees (2021: 52,294).

Training for Success (TFS) is a QQI Level 5 course which is run by Epilepsy Ireland in Atlantic Technological University Ireland (ATU), Sligo (previously IT Sligo). The course is funded by Mayo Sligo Leitrim Educational Training Board (MSLETB). This one-year full-time course is for people with epilepsy who may experience difficulty in entering the workforce or pursuing further education due to the impact of their epilepsy.

In previous years Atlantic Technology University (ATU) Sligo held the contract for delivery with MSLETB, while Epilepsy Ireland delivered the course on behalf of ATU Sligo. With the changeover to the new ATU structure, we were notified that ATU Sligo could no longer hold the contract with MSLETB. After negotiations with MSLETB, it agreed to take on the contract for delivery of the course commencing September 2022 with ATU Sligo agreeing that the course could be delivered on campus. Discussions are ongoing on the viability and sustainability of continued delivery of the course into the future. Demand for the course has decreased in recent years due to the wide range of further education opportunities available and the focus on integration of those living with chronic conditions into mainstream offerings.

Operating since 1998, TFS has been a key offering of our service and one which has had positive outcomes over the years, with 85% of those who successfully complete the course going on to further education or employment. Modules include Epilepsy Management, Research and Study Skills, Word Processing, Communications, Teamwork, Health and Safety at Work, Internet, Customer service & Work Experience. Students were back on campus throughout 2022 following in-person restrictions due to Covid 19 with eight students beginning the 2021/22 term in September 2021 (with three completing the year). Six students began 2022/23 programme in September 2022.

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, disability professionals and others. We distribute a range of information resources including our 'Education Information Pack – An Epilepsy

DIRECTORS' REPORT

Resource for Pre-school, Schools, and Colleges' and our 'Epilepsy in the Workplace' guide. During 2022, we also worked on updating our resources for healthcare professionals, and a new pack will be launched in 2023.

Alongside this, we also provide epilepsy awareness presentations for schools, medical institutions, workplaces and other settings where a need is recognised. In 2022, we delivered a total of 119 talks to schools, preschools, and other education settings with 3,271 people attending (2021: 160; 3,100).

The adoption of online tools in recent years has enabled us to greatly expand the number of people we can reach with special themed events of interest to people with epilepsy and their families.

Using our strong relationship with the medical community and the local connections that have been established in communities across Ireland, we organised 122 workshops, seminars, and information sessions during 2022, with 2,097 people attending (2021: 95; 2,745). Topics included employment rights and job search skills; wellbeing for women with epilepsy; epilepsy & memory; anxiety in children; study skills; infantile spasms and a parents' seminar. This also includes seven 'joint education sessions' co-delivered by FICROs and Advanced Nurse Practitioners for people recently diagnosed with epilepsy, a successful model of collaboration between EI and HSE professionals.

Two of our main annual events also returned in 2022 for the first time since 2019. The popular Family Fun Day was held at Dublin Zoo in July, with 140 people attending. The National Conference was a hybrid event in September, attended by 90 people in person and almost 200 online. Presentations included latest developments in epilepsy, new research on the blood-brain barrier, the role of seizure detection devices and resilience in managing epilepsy.

1.2 Identify and fill gaps in epilepsy service needs

Alongside established services outlined above, there were a number of new developments launched in 2022. These included our 'Mid-Morning Mindfulness' sessions and our Get ChARTy group sessions.

Epilepsy can be a stressful condition for many, and the practice of mindfulness can be a useful technique to help recognise the challenges that epilepsy can bring, and how they can be overcome. The offering of weekly online mindfulness sessions throughout 2022 proved to be extremely popular and successful, with 537 attendees taking part.

Our 'Get ChARTy' project was specifically targeted at children/young teens with epilepsy. It can be difficult for children with epilepsy to meet others living with the condition, and this was the main reason behind creating this programme. The events enabled 10–13 year olds living with epilepsy to meet with others informally and do some art at the same time – all from the comfort of their home. The sessions were led by Creative Art Therapist, Nichola Mooney and supported by our Community Resource Officers. Like the mindfulness sessions, the project proved to be extremely popular, with 94 attendees across the year. Because epilepsy can have an impact on the whole family, we also organised five creative arts-based workshops for siblings of children with epilepsy in 2022, in association with SibShops and a Community Resource Officer. These new offerings will continue in 2023.

DIRECTORS' REPORT

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.

Although Epilepsy Ireland has always strived to ensure that people with epilepsy and their families are at the heart of all we do, and to ensure that the lived experience of epilepsy is reflected in our priorities and goals, it is only since 2022 that this has been included as a core strategic aim. This ensures that the board, management and staff are mindful at all times of the importance of understanding the needs of the epilepsy community and planning our work accordingly, with a stronger emphasis on engagement and a greater role for volunteering.

In 2022, we consulted with our members and service users on a range of projects and activities including the theme for International Epilepsy Day (IED); reviewing the outcomes of the IED campaign; and topics for our National Conference. In addition, the priorities of our most recent research call which was completed in 2022 resulted from a consultation process in 2021. Our CROs draft annual plans based in part on feedback received in their areas from service users and others. Our advocacy work has been given greater priority on our website, in particular by providing greater opportunities for members and service users to get involved directly in our campaigns. The 2022-2026 Strategic Plan also included a detailed consultation process with members of all our stakeholder groups.

In terms of engagement, upcoming objectives from the Strategic Plan to build on the above include:

- Reviewing our membership model.
- Establishing a Service User Consultation group.
- Updating our volunteer policy
- Setting up and conducting annual surveys to establish needs, priorities, satisfaction and performance feedback.

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 and reduce the stigma of the condition (e.g. via personal stories, media engagements), support advocacy issues and participate in epilepsy research. These volunteers also take part in consultations as outlined above. At the end of 2022, we had 120 volunteers registered for these activities, and we communicated with the group monthly by email on the latest developments and volunteering opportunities.

The personal experiences of 10 of our media volunteers were the central focus of National Epilepsy Week which took place during May 2022. The theme of the week was #EpilepsyTogether and aimed to show how by working together, we can create greater awareness around a common condition and demonstrated how support & understanding from family, friends, colleagues, healthcare professionals, teachers and employers can be crucial to a person's journey with the condition.

Volunteer-led fundraising such as organizing events, participating in EI-organized 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. A Facebook group was set up in 2022 to encourage greater communication between fundraising volunteers.

DIRECTORS' REPORT

We acknowledge the contribution of our fundraising volunteers through our social media channels and highlight their efforts in our quarterly members newsletter. We also give an annual Volunteer of the Year award to acknowledge the outstanding contributions of an individual volunteer or a group of volunteers in support of our organisation. At our 2022 annual conference, the Young family from Co. Wexford were awarded the Volunteer of the Year award in recognition of the outstanding fundraising and awareness work carried out in memory of Louise Young, who died from Sudden Unexpected Death in Epilepsy (SUDEP) in 2021. Louise had been an active fundraising and media volunteer for Epilepsy Ireland and since her untimely passing, Louise's family and friends have continued Louise's work with great commitment and success. The award was a small acknowledgement of our appreciation of Louise's work, and all the work that has been continued in her name.

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 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 2022 under each of the four objectives of the 2022-2026 Strategic Plan.

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

Key components of the HSE's Slaintecare programme to reform health services include better integration and coordination across all care settings; a focus on early intervention; and individualised, holistic person-centred care designed around the needs of the patient.

Epilepsy Ireland has an important role to play in the development of epilepsy services to achieve these HSE objectives and we have a long and successful track record of working with HSE services to develop and improve service provision. We want to ensure that our community-based services are engrained as a key component in the wider care of people with epilepsy.

Currently we work in tandem with the HSE in delivering education programmes ('joint education sessions') for people who are newly diagnosed. These sessions, highlighted in 1.1 above were developed with funding from the Slaintecare Integration Fund in 2020 and are co-delivered by our GPs and Epilepsy ANPs. While funding has now ended, the project is a model of collaboration we hope to build on in future to ensure that people with epilepsy are provided the best possible education and support as early as possible in their journey. 7 of these sessions were held in 2022.

In addition, we continued to fund the Registered Advanced Nurse Practitioner (RANP) for Women with Epilepsy based at Beaumont Hospital, and we continued to engage with the HSE's National Epilepsy Clinical Care Programme and Epilepsy Electronic Patient Record (EPR) Governance Group. During 2022, HSE and stakeholders with an interest in the EPR including Epilepsy Ireland came together to develop a proof of concept for a new EPR that would better meet the needs of patients and professionals and work continues into 2023.

Other collaborations during 2022 aimed at improving the care of people with epilepsy and knowledge of the condition included:

- Collaboration with the HSE's Women & Infants Health Programme on a project to identify and meet the information needs of women with epilepsy.

DIRECTORS' REPORT

- Working closely with the Irish Epilepsy League on advocacy issues (see 4.1) and presented on Epilepsy Ireland's work at the League's annual expert day in September. The presentation focused on how patients and the medical community can work together to improve the lives of people with epilepsy across Ireland.
- Collaboration with the International Bureau for Epilepsy and International League Against Epilepsy on the organising of the 2023 International Epilepsy Congress to be held in Dublin.
- Working with UK epilepsy charities on the planning for National Epilepsy Week; with SUDEP Action to promote the Epilepsy Deaths Register for Ireland, the international Infantile Spasms Awareness Network on Global Infantile Spasms Awareness Week and with the US-based Anitz Kaufmann Foundation to organise Purple Day™ activities in Ireland.
- Board membership of the Neurological Alliance of Ireland (Director of Services) and the Disability Federation of Ireland (CEO)

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

Buccal Midazolam 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.

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 drivers, employers/employees (working alongside a person with epilepsy), community workers, facilitators of extra-curricular activities in the community and more.

The aim of the training programme is for participants to develop a greater understanding of epilepsy, understand the role of the emergency rescue medication and receive instruction in the correct administration of BM. The training is delivered by Epilepsy Ireland's Training Manager and Community Resource Officers.

The programme adheres 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. All our staff have completed 'train the trainer' training and undertake bi-annual refresher training from Quarners UK.

As part of the training, trainees are observed and tested throughout the day. On successful completion of the training, attendees 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 arranged.

The programme has grown exponentially over the years and has become a core part of our work at Epilepsy Ireland. In 2022, 2,536 professionals took part in this important training through 736 training sessions (2021: 3,346; 271).

Developments in 2022 included work on an online booking system (active from Q1 2023), training for new CROs recruited during the year, and accreditation through the Nursing and Midwifery Board of Ireland (NMBI).

Epilepsy Ireland's Community Resource Officers also deliver BM information sessions for parents and carers in all regions of the country to help ensure that parent/carers know how to correctly administer this increasingly common rescue medication. In 2022, 30 individual information sessions were delivered by our team with 171 parents/ carers attending (2021: 55;194)

DIRECTORS' REPORT

Other training provided in 2022 included epilepsy awareness training delivered to students in RCSI, Nursing students in UCD, Waterford and Athlone, 3rd year students in Medical Health/Biosciences in UCC and 2nd year students in Occupational Therapy in UL.

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

Since 2009, Epilepsy Ireland has operated a Research Funding Scheme, investing in high quality, high-impact Irish epilepsy research. Studies funded have included basic, clinical, psychosocial, genetic and health services research. The scheme aims to support research that has the potential to add significantly to existing knowledge into the causes, cures, care, treatment, impact and effect of any type of epilepsy, including SUDEP. At the beginning of 2022, the Scheme had historically supported 15 projects with a total investment of over €1.15m.

2022 was a landmark year with a record five new projects co-funded by Epilepsy Ireland during the year. These new investments take our total investment (including future commitments) to over €1.5m.

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). In September 2021, we announced our 8th Research Call under the JFS. Applications were requested for 1-3 year projects to a maximum of €50,000 p.a. Following a consultation with EI service users, the following priorities were set for the call: SUDEP & Epilepsy Mortality; Cannabinoids in Epilepsy; Epilepsy in Women; Psychosocial aspects of epilepsy; and Genetic and molecular mechanisms of epilepsy. A total of six proposals were received and in early 2022, an international peer-review of the applications was undertaken. In March, our Research Review Committee, chaired by Prof. Martin Brodie (Scotland) met and recommended three projects for submission to the JFS.

Following the HRB's review of all charity applications received, two of the three projects were selected for funding:

- Predicting and monitoring outcomes in Autoimmune Encephalitis (POTA); Principal Investigator - Prof Norman Delanty, RCSI; €149,924 investment over three years (50% EI, 50% HRB). 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, RCI; €91,286 investment over three years (50% EI, 50% HRB). 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.

Both of these funded projects started in late 2022. In addition, Epilepsy Ireland partnered on three applications to the Irish Research Council's Enterprise Partnership Scheme 2021. 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.

All three of the applications were funded, as follows:

- miR-CDD: Molecular mechanisms, therapeutic targets and biomarkers for CDKL5 Deficiency Disorder (CDD); €36,000 EI investment over four years, led by Dr Omar Mamad & Erva Ghani (RCSI). 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; €32,509 EI investment over two years, led by Dr Cristina Reschke & Radharani Brannan (RCSI). The study aims to identify circadian

DIRECTORS' REPORT

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; €27,000 EU investment over three years, led by Prof Grain Doherty & John David Dalemeiro (RCSI). The study will investigate the validity and impact of the popular Empatica Embrace2 wearable device for seizure detection.

Work continued in 2022 on other projects previously supported by Epilepsy Ireland. Ongoing projects include:

- An Analysis of the Current Implementation and Societal Impact of Group 1 and Group 2 Driving Restrictions in both Newly Diagnosed and Established Patients with Epilepsy (Prof N. Delanty & Dr S. Klaus, RCSI). This study is looking at the impact of losing one's drivers licence due to an epilepsy diagnosis, and providing an evidence background for EI's advocacy work, described below. In 2022, Dr Klaus presented interim findings at the National Office for Traffic Medicine annual research conference.
- Epilepsy Mortality in Ireland (HRB, Dr Yvonne Langan). See Section 3.4.

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). This study, funded under the IRC's Enterprise Partnership Scheme, 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.

In addition to the above, in December 2022, the HRB confirmed funding for a study to be led by Dr Aisling Walsh, Department of Public Health and Epidemiology, RCSI entitled "Health information and education resources for women with epilepsy from preconception to postpartum". Total funding is €174,600, over two years of which €15,000 is provided by Epilepsy Ireland. The project is under the Applied Partnership Awards 2022. Epilepsy Ireland and the HSE's National Women and Infants Health Programme are both designated 'knowledge users' on the award. Funding was officially announced in January 2023.

This study, which will begin in 2023, proposes to identify, alongside women with epilepsy, their families and healthcare professionals, health information needs along the preconception to postpartum continuum. It will also identify and co-develop prioritised evidence-based resources to support women and health professionals during this period.

During 2022, we also helped connect researchers to people with epilepsy through our communications channels, produced a new research bulletin (magazine) for donors supporting our research activities, and 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 is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy and where no other cause of death can be identified. International studies have found that there is approximately 1 case of SUDEP for every 1,000 people with epilepsy annually, although estimates vary. Key risk factors for SUDEP 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.

DIRECTORS' REPORT

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. In 2022, SUDEP was included on the agenda for our National Conference. We also began a social media campaign on SUDEP awareness with monthly posts on various aspects of SUDEP gaining strong interaction.

SUDEP Action Day is an increasingly important day in our calendar to raise awareness of SUDEP amongst the entire epilepsy community, including healthcare professionals. In October 2022, we shared personal testimonies from siblings 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.

To reach the medical community, Katie Young, sister of Louise who died from SUDEP in 2021 spoke at the Irish Epilepsy League Expert Day to highlight the importance of having conversations with patients about SUDEP. We also wrote an article on SUDEP for the Hospital Professional News magazine.

Supporting research into SUDEP has consistently been highlighted by Epilepsy Ireland members and service users as a key priority for our research investments and in the latest call for funding applications, SUDEP was one of the priority areas. Currently, there are two active research projects supported by the organisation.

Dr Yvonne Langan (St James's Hospital/ Trinity College) is leading 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. This will be the first countrywide examination of SUDEP incidence in Ireland, and while data collection was affected in 2020-2021 due to public health restrictions, work continued during 2022. It is hoped to have results in 2023 and I will use the data to further increase awareness of epilepsy-related deaths and to emphasize the need for people with epilepsy to have equitable access to expert neurology care. We hope that this study, when published, will be a catalyst for long overdue collaborative action on reducing epilepsy-related deaths in Ireland involving Epilepsy Ireland; healthcare professionals; the HSE; Department of Health and other stakeholders.

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. In 2022, renewed efforts were undertaken by Epilepsy Ireland to promote the Register on our website and social media channels, in particular around SUDEP Action Day, when we made a specific appeal to bereaved families to provide details of their loved one to the register. As healthcare professionals can also make returns, we also worked with the Irish College of General Practitioners to arrange a feature about the register in their member's magazine, Forum and we wrote to all county coroners to remind them of the EDRI. As a result, 14 new submissions were made to the register.

We also collaborated with SUDEP Action on plans to make their evidence-based, validated SUDEP and Seizure Safety Checklist available in Ireland. The tool is used by clinicians to support discussions about risk with people with epilepsy. The aim is that the checklist will be made available in Ireland in 2023 via Epilepsy Ireland, supported by the fundraising efforts of the Corrigan family, who organized the 'Cycle For Shane' fundraising event in 2022 in memory of Shane Corrigan who died from SUDEP in 2018.

DIRECTORS' REPORT

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.

At Epilepsy Ireland, we aim to transform perceptions of epilepsy through our awareness raising campaigns throughout the year and advocate for changes to policy to positively impact on the lives of people living with the condition.

Our flagship public awareness campaign centres around International Epilepsy Day in February and in 2022, we aimed to build on the key seizure first-aid words of "Time, Safe, Stay" that were introduced for our Epilepsy Day 2021 campaign. Our campaign was an eye-catching exaggeration of how people with epilepsy can be treated differently due to their condition and how sometimes, the public can try and protect people with epilepsy in the wrong way. Three scenarios were used to show how protecting people with epilepsy doesn't have to be difficult if you know about Time, Safe, Stay. Our volunteers Wayne,

Lisa & Lucy fronted the campaign – which saw them don a suit of armour; bubble wrap; and be entrapped in a Zorb ball for videos and images to highlight the key message.

The campaign was released across social media with promoted videos on Facebook, Instagram, YouTube, Snapchat and TikTok – as well as digital advertising on the RTE Player and in other leading titles such as the Irish Times. Audio adverts promoting the key message also ran on Today FM and Spotify, while organic media coverage was also secured across a number of leading titles such as the Irish Independent, RTE Drivetime, several regional media outlets and a fantastic piece on News 2day featuring a young EI service user and her classmates. Across social media, the campaign had a total of 2.5 million impressions, while one video alone on Facebook had just under a quarter of a million views.

The campaign was later shortlisted for a Kinsale Shark award – a leading advertising award and although ultimately unsuccessful, to be nominated was a huge acknowledgement of its impact. We would like to thank all our volunteers who supported the campaign by sharing their stories with local media and in particular Wayne, Lisa & Lucy for being the faces of the campaign.

Other awareness campaigns held in 2022 included:

Brain Awareness Week (March):

Led by the Neurological Alliance of Ireland (NAI), a collaboration of over 30 neurological charities, Epilepsy Ireland lent our support to the central messaging of the week highlighting the TEAM theme designated by NAI. We used the theme to highlight the work of the EI team, the importance of neurology teams and the need for improved access to these teams as outlined in the NAI's Patient Deserve Better Campaign.

National Epilepsy Week (May):

Aimed more so at the epilepsy community rather than the general public, the theme of the week was #EpilepsyTogether and aimed to show how by working together, we can create greater awareness around a condition which affects 45,000 people in Ireland. 10 personal experiences helped to highlight how support & understanding from family, friends, colleagues, healthcare professionals, teachers and employers can be crucial to a person's journey with epilepsy.

DIRECTORS' REPORT

SUDEP Action Day (October): See 3.4 above.

Infantile Spasms Awareness Week (December):

We shared two personal stories of families whose children have developed Infantile Spasms. The stories were a powerful insight of how these seizures can present and the impact they can have. The stories encouraged new and prospective parents to learn more and to know the signs of infantile spasms. We also arranged a special information event on Infantile Spasms with paediatric neurologist, Dr Mary O'Regan a med at both new/prospective parents and health professionals.

Several advocacy campaigns were progressed during 2022

Work on the Sodium Valproate campaign continued alongside our colleagues in OACS Ireland, and progress was made on each of the key issues central to the campaign. In 2020, the Minister for Health committed to setting up an inquiry into the historical licensing and prescribing of sodium valproate in Ireland and discussions with the Department of Health were ongoing throughout the year on a Terms of Reference for the inquiry. Terms of Reference were agreed with the Department late in the year, and as the year ended, we awaited their approval at cabinet level.

2022 also saw the establishment of the Sodium Valproate Stakeholder Group by the Department of Health. The establishment of this group has been a key advocacy priority for Epilepsy Ireland for many years. The aim of the group is to bring all relevant stakeholders with an interest in the safe prescribing of valproate together to collaboratively review existing risk minimisation measures and to recommend new measures as needed to further reduce the risks of children being born with valproate-related disabilities. This group met for the first time in November and its membership is made up of patient groups; state bodies; and healthcare professionals – all of whom have a role to play in the care of women with epilepsy. Finally, in 2022, we also received confirmation that funding was approved for the recruitment of the three remaining Epilepsy Nurse Specialists, which were first committed to in 2018. These posts, when filled, will help improve the implementation of the Sodium Valproate pregnancy prevention programme.

In 2022, there was a major step forward in our long-standing advocacy campaign to improve reasonable accommodations for students with epilepsy sitting state examinations. In particular, we had called for deferred Leaving Certificate exams to accommodate students who had been unable to complete an exam as result of a medical issue such as a seizure at the time of the original exam.

Considerable progress was made on this matter in 2022 with the introduction of deferred examinations by the State Examinations Commission (SEC), with access available for students who had medical emergencies. Seizures were specifically included as an example of such a medical issue. Unfortunately, the guidelines distinguished between students who had a seizure prior to the exam and those who had a seizure during the exam, with the latter case not eligible for a deferred sitting. According to the SEC, this is to protect the integrity of the exams. This led to major issues with how the criteria were applied – with direct examples of students, including at least one student with epilepsy, being treated differently in similar circumstances. We highlighted in the media the case of Rachel Langan, a student who had a seizure during an exam and was told that she would not have access to the deferred sitting, even though another student who was unable to complete an exam due to appendicitis was given access to a deferred sitting.

We continued to advocate for changes to be made to prevent these issues arising in future, as well as for other improvements to the scheme. Central to this was to abolish the distinction between *before* versus *during* the exam. Work on these issues continued throughout 2022 and at the end of the year, meetings with both the

DIRECTORS' REPORT

SFC and the Minister for Education were in the process of being arranged for the year ahead. We hope to have further progress on this issue in 2023.

At the beginning of 2022, we met with the Minister for Social Protection to discuss our proposals around improving access to the Free Travel Scheme for people with epilepsy. This is another long standing issue that continues to impact on the people we support. Currently, there is no direct access route to the Free Travel scheme for people with epilepsy who are prohibited from driving due to their diagnosis.

Following this meeting, Department officials undertook exploratory work on proposals put forward by Epilepsy Ireland to address this issue. At the end of 2022, the Minister indicated that a final report is being prepared on our submission and potential paths forward. We will continue our work on this in 2023 and we hope that there will be positive developments during the year.

A range of other advocacy activities were undertaken in 2022, including:

- Confirmation from the Office of the Attorney General that harmful online content designed to trigger seizures in people with epilepsy would be considered as assault under the Non-Fatal Offences Against the Person Act, 1997. This clarified our concerns over the Online Safety Bill, which did not specifically address the issue.
- We made a submission to the National Centre for Pharmacoeconomics supporting reimbursement of Cenobamate, a new medication indicated for the treatment of refractory focal onset seizures. Later in 2022, the NICE recommended Cenobamate for reimbursement.
- We made representations to the Health Products Regulatory Authority (HPRA) on the issues of generic substitution of anti-epileptic drugs (arising from a decision to add Levetiracetam 100mg/ml oral solution to the list of interchangeable medicines) and on medicines shortages. During the year, shortages were a common theme and EI worked with the HPRA and our service users to ensure effective communications in relation to epilepsy medications.
- We played an active role in the NAI's Patients Deserve Better campaign which seeks to address the shortfall of neurological specialist nurses in Ireland. This included a presentation by an EI volunteer at a Leinster House briefing to elected representatives.

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

In 2022, our epilepsy.ie website had a major facelift. The works were carried out to improve the accessibility of the site for those who may be visually impaired, while a particular focus was made to improving how the site performs on mobile devices. According to our analytics, the majority of people visiting our website now do so via their mobile devices so this was a timely and important piece of work to undertake across the year. A new analytics system was also put in place, giving a clearer picture of site traffic and the most popular content on the site. Website development and additions will continue to be reviewed throughout 2023.

Our social media channels continue to be an important avenue for our organisation to increase our visibility. As we approached the end of 2022, we had almost 23,000 followers on Facebook; 5,000 on Instagram; and during the year, we passed 5,000 followers on Twitter. We also established a new presence on TikTok, as well as continuing to grow our presence on LinkedIn. We also designated a number of priority topics that we posted on each month across our channels including seizure first aid, SUDEP, our regional services; and more.

Monthly e-mail newsletters were distributed highlighting news and events, with additional issues distributed around key awareness activities/ events. Four editions of our members' 'Epilepsy News' magazines were produced and distributed, in addition to a research bulletin highlighting EI's recent support of Irish research.

DIRECTORS' REPORT

We continued to actively engage with the media on relevant news items, awareness campaigns and advocacy issues.

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 support staffing and costs relating to many of our support and education services. Funding cuts during the last recession which have never been restored, combined with increasing costs, inflation and increased demand for our services in the interim has meant that HSE funding does not cover the full cost of the contracted services.

We have worked to minimise funding shortfalls in recent years through cost control measures, fundraising and new funding sources e.g. the Scheme to Support National Organisations, the Covid-19 Stability Fund and the Slanterare Integration Fund. However, in 2022, there was a funding shortfall of €53,123 (2020: €34,592), which has been met by utilising unrestricted reserves.

During the year, we supported ongoing efforts in the sector to address ongoing HSE funding issues, in particular through our work with the Disability Federation of Ireland (DFI) who are represented on the HSE's Dialogue Forum with Voluntary Organisations. We participated alongside the HSE and three other Section 39 organisations in one of several full-day facilitated workshops commissioned by the Dialogue Forum in November. The purpose was to identify how relationships between the HSE and voluntary providers might be improved in the future, including through funding arrangements. A report will be presented to the Dialogue Forum in early 2023 on feedback from the workshops. We remain hopeful that progress will be made in 2023 to address long standing funding concerns relevant to Section 39 organisations like Epilepsy Ireland and we are encouraged by news at the end of 2022 that €100m is being set aside for "once off additional support" for Section 39 and residential services.

Another important source of core funding is SSND funding. First obtained in 2019 it was renewed by Pobal for a further three-year period from July 2022 at the increased rate of €254,428 (2019-2022: €233,304). This funding supports key roles within the organisation.

Total non-grant income in 2022 was €593,597 (2021: €706,187). This includes income from fundraising activities, donations, in-kind donations, training income, membership, interest received and other miscellaneous income.

Following two very difficult years due to the Covid-19 pandemic, the fundraising environment improved slightly in 2022. Community fundraising activities such as church gate collections and Rose Week returned, and while recruiting volunteers was a challenge, these activities were vital in reducing the organisation's overall deficit at year end. Several fundraising activities however performed below expectations and there was a notable shift away from online fundraising which was vital during 2020 and 2021 towards organised supporter-led events.

Notable supporter events during the year included two separate Malin to Mizen cycles - one by Paul Klewan

DIRECTORS' REPORT

and Sean Doolan from Offaly, who took on the challenge in recognition of their niece Becky who lives with epilepsy, raising over €6,000 and one by members of East Cork Tribe in memory of the late Marie Sexton who passed away from SUDEP in 2021, raising over €13,000. Mairead Power raised over €5,000 climbing Kilimanjaro, the family and friends of the late Niall Coughlan Memorial raised almost €20,000 while Seany Burns from Clare raised over €4,000 taking part in an Ironman challenge. These are just some of the many individuals and groups who volunteered their time, expertise and efforts to raise vital funds for the organisation during the year.

Our monthly Time for a Break draw, members' raffle, and Purple DayTM continued to be important parts of our fundraising mix. Corporate support in 2022 included Edwards Lifesciences, HSBC, Neuraxpharm, LivaNova, Evelyn Partners and Turkish Airlines.

We would like to express our immense gratitude to all those who supported our work throughout 2022 – without your efforts and contributions, we would not be able to do the work that you see outlined in these pages.

The board and management are conscious that implementing our Strategic Plan objectives requires developing and diversifying our income generation activities. Key strategies include expanding our corporate partnerships, growing regular and digital giving, and by embracing new techniques and technologies. We also aim to develop Purple DayTM into a flagship annual fundraising event. While there were some positive developments on these objectives in 2022 (e.g. a solid Purple Day campaign, a new fundraising system implemented, new corporate supports), progress was also hindered by the departure of key fundraising staff from our small team during the year, and a challenging recruitment environment.

Income from our training programme in epilepsy awareness and the administration of Buccal Midazolam (See 3.2 above) is another vital source of funds for the charity and in 2022, this amounted to €166,792 (2021: €151,050), returning to pre-pandemic levels.

Capacity and Governance

Strategic Aim 6:

Demonstrate highest standards of governance & ensure structures are in place to meet objectives.

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

The Board is committed to the highest standards of governance and understand that this is a key obligation, not only in ensuring best practice in fulfilling the organisation's mission, but also in maintaining the trust and confidence of members, service users, volunteers and donors.

Epilepsy Ireland maintains the Charities Institute Ireland 'Triple Lock' standard of compliance with the Guidelines for Charitable Organisations on Fundraising from the Public; the CRA Governance Code, and preparing our financial statements in accordance with SORP for charities. The Board first declared the organisation's full compliance with the CRA Governance Code in 2021. We annually complete the Charities Governance Code Compliance Record. This was reviewed in July 2022 and full compliance was again declared by the Board.

Since 2021, Epilepsy Ireland also maintains the Improving Quality Foundation quality mark. IQ is a standard developed specifically for small non-profit organisations, assessing the organisation's governance and management under the indicators of accountability, welcoming, effectiveness and sustainability. We previously

DIRECTORS' REPORT

held the Trusted Charity standard from 2015-2021.

In accordance with our policy on external audit, a competitive tender process was undertaken in 2022 for the provision of audit services, resulting in the appointment of Mazars as our new auditors from 2022.

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. In 2022, a board evaluation was also undertaken.

Activities of the Board of Directors 2022

The Board operates in accordance with agreed governance policies & procedures and with reference to strategic and operational plans.

Eight board meetings were held in 2022 (2021: Seven). Seven meetings were held remotely, and one was held in-person. During the year, the board:

- Monitored progress at each board meeting against the 2022 operational plan and budget
- Reviewed and approved updates to over 20 internal policies & procedures per review schedule
- Reviewed and agreed the organisation's risk profile (on two occasions) and approved actions to mitigate identified risks.
- Finalised and approved the organisation's new Strategic Plan for 2022-2026 in April. Approved an updated operational plan and budget for the remainder of 2022, taking account of the goals of the plan.
- Agreed to commit investment in new research projects (see Section 3.3)
- Reviewed and updated membership of the organisation's sub-committees.
- Reviewed and approved proposals on staff salaries, with reference to available benchmarking data and available resources.
- Approved new travel reimbursement rates for staff/ volunteers.
- Agreed an updated 12 month Board recruitment & development plan
- Approved the organisation's full compliance with the CRA Governance Code.
- Approved the appointment of Mazars as the charity's new external auditors.
- Re-appointed Officers (Chairperson, Secretary and Treasurer) for a further 3-year term in accordance with the Constitution.
- Completed a board performance review.
- Agreed to establish a Service User Consultation Group (from 2023).
- Received detailed departmental updates from management team/ staff members at several meetings, as well as external updates from the International Bureau for Epilepsy (IBE) and Prof. Colin Doherty.
- Discussed medium/long term sustainability concerns and agreed to further review cost-reduction measures to be presented by management in Q1 2023.
- Approved an annual plan and budget for 2023

6.2 Strengthen our organisational structure and capacity.

Unfortunately, in common with many other Section 39-funded organisations, retention and recruitment of staff was a significant challenge in 2022.

DIRECTORS' REPORT

In total, 11 different vacancies arose in our team of 24 during the year. While these included one planned retirement and subsequent internal promotion, significant efforts were required to replace, induct and acclimate departing staff, while ensuring that the impact on services and operations was minimised. At year end, four vacancies existed, including two in our fundraising team, one Community Resource Officer post and one communications post. As a result, a planned review of existing staff structures to reflect post-Covid operations and Strategic Plan goals did not take place. However, seven successful appointments were made during the year including management posts in finance and in training.

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. The Board agreed to a 3% general increase in salaries, effective from 1 July 2022. The decision was taken with reference to the benchmark data and several internal and external factors, including the economic environment, EI's financial outlook and ability-to pay, and the fact that there had been no increase in salaries since 2018.

Sub-committee roles and their membership was also reviewed by the board in 2022. Two new (non-director) members were appointed to the Finance & Audit sub-committee, and a recruitment process was undertaken to add legal/HR expertise to the board. These skills had been identified as the key gap in the board's existing knowledge and expertise set. The board also undertook an evaluation exercise to better understand and improve its effectiveness.

6.3 Invest in our technology needs.

The major focus in 2022 under this objective was the implementation of the CHAMP CRM system for fundraising and membership management. Work also began on adapting the system to manage our training activities. The system was integrated into our website, and in addition to this, several other functionality and layout improvements were made to the site (see Section 4.2 above). A new HR system was also introduced in 2022 to simplify the management and recording of employee records and activities.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Brainwave the Irish Epilepsy Association, trading as Epilepsy Ireland is a 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 (CHI NO. 6170) and is registered with the Charities Regulatory Authority (Registration No. 20010553).

DIRECTORS' REPORT

Board of Directors

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

The board is comprised of 12 volunteer members (as of 31 December 2022), drawn from a variety of backgrounds, skillsets and experiences. In recent years, the board has focused on achieving greater balance in terms of skills, association with epilepsy, gender, age, geography and ethnicity. At present, there is a 50:50 gender balance, and the recruitment of younger members has been prioritised. Eight board members have a direct personal connection to epilepsy (i.e., either they or a close family member lives with the condition).

The board will continue to work towards its aims of ethnic and geographic diversity.

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 constitution (2020) specifies that board members may ordinarily serve up to two four-year terms (from the date of adoption in 2017). The constitution also governs 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, who manage recruitment processes, review applications, interview and vet candidates and make recommendations to the board. Recruitment strategies in recent years have included seeking nominations from members, approaching existing volunteers and availing of the services of Boardmatch. An induction process is in place for newly appointed board members 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 member's first board meeting.

No new members were appointed to the Board in 2022, although at year end, a process was underway via Boardmatch to appoint new directors with legal and HR skills to the board.

It was with great sadness that we learned of the passing of former Epilepsy Ireland board member, Major General Vincent Savino Retd. in August. Vincent had resigned from the Board earlier in 2017 and had been a long serving board member and volunteer with Epilepsy Ireland. He originally became involved with the organisation in the 1980s, due to the fact that a close family member lived with the condition. He was instrumental in developing fundraising activities needed to support the work of the charity in the 80s and 90s, and was a source of great wisdom, sound judgement and strategic clarity during his time on our board of

DIRECTORS' REPORT

directors. 'Vinny' was an extraordinary man, held in great esteem by all who came to know him through Epilepsy Ireland and he remained throughout his life a wonderful ambassador for the condition. We will miss his commitment to the cause, his always sound advice, and above all, his wit and positive outlook. *Ar dheis Dé go raibh a anam.*

Board composition

As at 31 December 2022, the Epilepsy Ireland board members were:

Cathy Grievé (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 (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 of Paul lives with epilepsy.

Helen Behan

Helen brings a wide range of knowledge and expertise from her work in the Charity sector. She was diagnosed with epilepsy in 2015 and joined the Board in 2021.

Mark Dowdall

Mark initially became involved with Epilepsy Ireland as a result of a family member's epilepsy diagnosis. He was elected to the Board in 1999 and was Chairperson from 2013 to 2019. Mark's professional background is in technology, financial services and banking.

Paul Fahey

Paul is a Chartered Director and member of the Institute of Directors Ireland. A pharmacist who previously owned and operated a pharmacy business for over 25 years, he currently provides consultancy services to the health sector. He served as the President of the Pharmaceutical Society of Ireland from 2011-2013. He joined the Board of Epilepsy Ireland in 2020.

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 Neurophysiology 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 research and joined the Board in 2018.

Derry Gray

Derry, who has a family member with epilepsy, was elected to the Board of Epilepsy Ireland in 2014. He is a

DIRECTORS' REPORT

Partner and Head of the Management Consulting Department at BDO and served as the company's Managing Partner from 2011 to 2014. He was elected as President of Dublin Chamber of Commerce in 2016.

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.

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 recently 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. She joined the board in 2021.

Shane O'Brien

Shane joined the Board of Epilepsy Ireland in 2021. He has also been a member of the Finance & Audit sub-committee since 2019. He was diagnosed with epilepsy in 2015. He is a Chartered Accountant and a Chartered Tax Adviser.

Board Meeting attendance 2022

	Feb	March	April	May	July	Sept	Oct	Dec	Total
C Greve	Y	Y	Y	Y	Y	Y	Y	Y	8/8
C O'Dea	Y	Y	Y	Y	Y	Y	Y	Y	7/8
P Kenec	Y	Y	Y	Y	Y	Y	Y	N	7/8
H Belian	Y	Y	Y	Y	Y	Y	Y	Y	8/8
M O'Connell	Y	Y	Y	Y	Y	N	Y	N	5/8
P Lahey	Y	Y	Y	Y	Y	Y	Y	Y	8/8
M Fitzgerald	Y	N	Y	N	Y	Y	N	Y	5/8
D Gray	Y	Y	Y	(N)	(N)	(N)	(N)	(N)	1/8
A Kealy	Y	N	Y	N	Y	N	Y	Y	5/8
A Kilroy	Y	Y	Y	Y	Y	Y	Y	Y	7/8
M King	Y	N	Y	Y	Y	N	Y	Y	6/8
S O'Brien	Y	Y	Y	Y	Y	Y	Y	Y	8/8
V Thomas	(N)	(N)	(N)						0/3

Y Present

N Apologies

(N) Apologies due to ill-health

No longer director

Role and activities of sub-committees

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

DIRECTORS' REPORT

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 2022, the committee met on seven occasions. It made recommendations on annual budgeting, financial aspects of the five year strategic plan, risk management, financial controls, salary reviews and expenses review. It also led on the tender process for audit services. Two new external members were appointed to the sub-committee from January 2023 – Owen McCarthy and Allan Barrett.

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 twice in 2022, focusing on board recruitment, board skills analysis, recommending a board development report to the board, and review of certain internal policies prior to board review.

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 2022, focusing on reviewing the organisation's risk register and risk policy, health and safety matters, complaints, plans for the IQ Quality framework, and a review of the committee's terms of reference.

Remuneration sub-committee:

The sub-committee sets the CEO's objectives, appraises and reports to the Board on performance and recommends on management remuneration. The sub-committee did not meet in 2022.

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 2022.

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.

The Remuneration sub-committee is responsible for setting the CEO's remuneration. It also reviews the remuneration of members of the senior management team, in conjunction with the CEO. The CEO's remuneration was set in 2016, and subsequent general salary increases approved by the board have not applied to the role.

DIRECTORS' REPORT

FINANCIAL REVIEW

Results for the Financial Year

	2022	2021
	€	€
Net (expenditure) for the financial year	(108,093)	(25,198)

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

A deficit of €108,093 was recorded in 2022. While this is in excess of the 2021 deficit of €25,198, it is significantly lower than the deficit budgeted at the beginning of the year. Deficits recorded in 2021 and 2022 followed three successive years (2018-2020) where surpluses were recorded.

The 2022 outcome was the result of a reasonably positive performance in income generation (see detail in Section 5 above) and successful efforts to minimise costs to ensure expenditure was under budget.

As highlighted in Section 6.2 above, staff retention was a significant challenge during the year and one effect of this was that overall staff costs of €1,014,813 were lower than both 2021 (€1,034,668) and 2022 expectations. The nature of our work is highly dependent on direct staffing resources, typically accounting for approx. two-thirds of all expenditure. We employ skilled, experienced service and training staff to deliver on our objectives in these areas, supported by professional expertise in fundraising and administration. In addition, fundraising and administration costs were kept under budget, while some expected programme costs were not incurred due to projects being deferred to 2023 e.g. aids and appliances scheme, SUDEP & Risk checklist, healthcare professional education resources. It should also be noted that in 2022, our investment in research of €83,850 exceeded that in recent years.

Reserves and Investments

As detailed in Note 21 to the Financial Statements, total reserves at the end of 2022 are €1,463,498. This consists of restricted funds of €86,405, designated funds of €435,093 and an unrestricted operational reserve of €942,000.

Restricted reserves include amounts relating to HSE (including National Lottery) and other state funding which is to be applied for grant agreed purposes. Balances on Community Foundation and County Councils relate to depreciation charges to be incurred in future years. Restricted amounts also include funds raised by the Young family of €47,644 in 2021 and 2022 which are to be used for the establishment of an expanded 'aids & appliances' scheme.

The Board has designated reserves for utilisation in special strategic activities including undertaking epilepsy awareness campaigns (€70,482); providing funding for current and future research projects (€114,611); providing and sustaining an expanded Aids & Appliances scheme (€50,000); and to meet future costs for upgrading/relocating the charity's head office (€100,000). The Board also maintains a reserve to facilitate implementation of the organisation's Strategic Plans (€100,000).

The most recent review of designated reserves by the board was in 2021 and a further review is planned for Q2 2023 to examine the appropriateness of the designations and the amounts designated. At the end of 2022, variances between the policy and actual reserves were:

- Awareness Campaigns: €100,000 designated, €70,482 actual.
- Research funding: +188,082 designated, €114,611 actual.

DIRECTORS' REPORT

Key existing commitments relating to designated reserves relate to future committed expenditure of €174,037 in epilepsy research (2023-2025).

Epilepsy Ireland's Investment policy (2021) stipulates that the charity holds at least six months of planned operational expenditure as an unrestricted operational reserve to ensure continued financial security and to provide for contingencies. The unrestricted reserve at the end of 2022 of €942,000 meets this stipulation, based on an anticipated operational expenditure of c. €1.5m.

The Investment policy also details the charity's 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 at 31 December 2022.

	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	€250,052	€871,753	€240,000

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 (€101,330) and Permanent TSB (€650,423) as well as €120,000 in 3-year State Savings Bonds. Medium term reserves consist of €240,000 in 4- and 5-year State Savings Bonds. Total cash at bank and in hand as at 31 December 2022 is therefore €1,002,805.

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 those risks. The register is reviewed regularly 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 risk register is reviewed twice a year and close monitoring is undertaken. The following are the most significant risks faced by the organisation, as outlined in the most recent review of the register (February 2023), along with a summary of mitigation actions:

Drop in Fundraising Income

Actions: Review role of Business Development & Sustainability sub-committee, address vacancies in fundraising department; develop income generation plan in line with Strategic Plan; close monitoring of fundraising activities and data including those which may be under-performing; develop "cases for support".

Poorly performing fundraising activities

Actions: As above; ensure adequate investment in fundraising activities

DIRECTORS' REPORT

Inadequate HSE funding. Overdependence on HSE income

Actions: Develop income generation plan in line with strategic plan; board discussion on medium-term contingency actions to reduce expenditure; ongoing engagement with advocacy efforts to increase Section 39 funding; review reserves policy in 2023; monitor and apply for new funding opportunities

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

Actions: Review volunteer policy and seek out funds to develop volunteer programme envisaged in strategic plan; launch service user consultation group and undertake service user satisfaction/ feedback surveys; periodic reviews of strategic plan; seek funding to enable expansion of staffing resources; expand training staffing in 2023.

Services discontinued or become obsolete

Actions: Review sustainability of Training for Success programme; implement online learning platform; ensure appropriate balance between online and in-person services; work towards launch of expanded aids & appliances scheme.

External Factors (i.e. Covid-19 pandemic; economic and political environment)

Actions: Review Business Continuity Plan and Crisis Communications plan; review investment policy/ deposits to protect against inflation; develop environmental & social policy; monitor potential Covid-19 developments.

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 a recovery in fundraising is partially dependent on the external political, economic and public health environments. The Board is confident that assumptions made in budgeting and planning for 2023 are appropriate and that it can take any further steps required including additional measures to reduce costs or utilise reserves if required

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 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. Further details can be found in note 3 to the financial statements.

Internal controls

The board has established procedures of compliance which addresses the board's wider responsibilities – 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. The most recent review was in October 2022

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 board. The budgeted income and expenditure are monitored to ensure alignment with plans and with financial resources available and forecasts are updated ahead of each sub-committee and board meeting.

DIRECTORS' REPORT

FUTURE PLANS

As outlined above 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.

Under each of the six strategic aims, our plans for the next four years (to end 2026) 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 the HSE 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 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

While gains have been made in recent years, 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 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 our communications are centred on a diverse range of personal experiences of epilepsy.

DIRECTORS' REPORT

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 services which has remained static for over a decade.

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, donors and all 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.

To achieve these goals, the Board will annually approve an Operational Plan and Budget based on the Strategic Plan, containing more specific goals and tasks for the year ahead.

Reports will be given to the Board at each of its meetings, progress will be monitored, and periodic evaluations of the strategic plan will take place. Where necessary, updates will be made to the plan at these evaluations to account for changing circumstances.

Some of the actions in the 2023 Operational Plan include:

- Provide one-to-one support services to >7,500 individual contacts.
- Develop mechanisms to measure impact of services
- Work with other stakeholders in organising the International Epilepsy Congress in Dublin in September 2023.
- Launch initial e-learning modules.
- Facilitate programmes on mindfulness and supports for children with epilepsy and their siblings
- Launch service-user consultation group.
- Collaborate with other stakeholders on advancing WHO IGAP implementation.
- Provide training for 3,000 healthcare professionals and teachers in epilepsy awareness and the administration of BM.
- Support and collaborate on 8 ongoing EI funded research projects
- Launch results of SUDEP Incidence Study
- Launch SUDEP Risk checklist in Ireland in collaboration with SUDEP Action.
- Organise and deliver awareness programmes including the flagship #EpilepsyDay campaign in February.
- Advance core advocacy campaigns including on free travel, exams and sodium valproate.
- Fill existing staff vacancies including in fundraising and meet fundraising target in budget
- Review and update Governance Code compliance records & maintain Triple Lock
- Conduct review of premises requirements.

DIRECTORS' REPORT

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 M. Dowdall
Mr P. Fahey
Ms M. Fitzsimons
Mr D. Gray
Mr A. Kealy
Mr P. Kehue
Ms A. Kilroy
Prof M. King
Mr S. O'Brien
Ms C. O'Dea
Major General V. Savino (resigned 1 April 2022)

Secretary:

Ms C. O'Dea

POST BALANCE SHEET EVENTS

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

ACCOUNTING RECORDS

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

DISCLOSURE OF INFORMATION TO AUDITORS

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

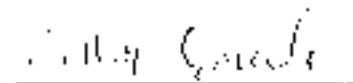
- A) So far as the director is aware, there is no relevant audit information of which the company's auditors are unaware; and
- B) Each director has taken all steps that ought to have been taken by the director in order to make himself/herself aware of any relevant audit information and to establish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

DIRECTORS' REPORT

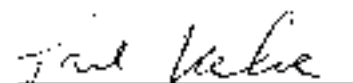
AUDITORS

The auditors, Mazars, Chartered Accountants and Statutory Audit Firm, having been appointed during the year, 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: 23 May 2023

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.

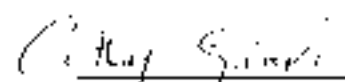
In preparing those financial statements, the directors are required to:

- 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.

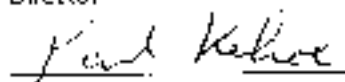
The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets, liabilities, financial position and surplus or deficit of the company to be determined 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 Grève
Director



Paul Kehoe
Director

Date: 23 May 2023

**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

Report on the audit of the financial statements

Opinion

We have audited the financial statements of Brainwave-The Irish Epilepsy Association T/A Epilepsy Ireland for the year ended 31 December 2022, which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and the related notes, 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 financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2022 and of its results for the year then ended;
- have been properly prepared in accordance with FRS 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland*; 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 Company 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 Company'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.

**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND (Continued)**

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 Company 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 Company 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 Company. We have nothing to report in this regard.

**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND (Continued)**

Respective responsibilities***Responsibilities of directors for the financial statements***

As explained more fully in the directors' responsibilities statement set out on page 32, 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 Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless management either intends to liquidate the Company or to cease operations, or has no realistic alternative but to do so.

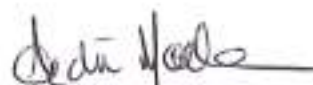
Auditor's responsibilities for the audit of the financial statements

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 Company'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 Company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Company and the Company's members, as a body, for our audit work, for this report, or for the opinions we have formed.

**Aedin Morkan****Date: 23 May 2023****for and on behalf of Mazars****Chartered Accountants & Statutory Audit Firm****Harcourt Centre****Block 3****Harcourt Road****Dublin 2**

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 2022

	Note	Restricted Funds 2022 €	Unrestricted Funds 2022 €	Total Funds 2022 €	Restricted Funds 2021 €	Unrestricted Funds 2021 €	Total Funds 2021 €
INCOME FROM:							
Donations and Legacies	4	23,439	200,509	223,948	51,765	224,362	276,127
Charitable Activities	5	935,529	174,196	1,109,725	826,193	266,165	1,092,558
Other Trading Activities	6	32,858	138,892	171,750	34,039	114,841	148,880
Investment Income	7	-	2,375	2,375	-	2,015	2,015
Other Income	8	-	22,242	22,242	-	12,800	12,800
Total		991,826	538,214	1,530,040	911,997	520,383	1,532,380
EXPENDITURE ON:							
Charitable activities	9(a)	1,065,234	360,954	1,426,188	1,008,844	332,765	1,341,609
Raising funds	10	25,274	186,671	211,945	33,971	181,998	215,969
Total		1,090,508	547,625	1,638,133	1,042,815	514,763	1,557,578
NET (EXPENDITURE)/ INCOME	13	[98,682]	(9,411)	(108,093)	(130,818)	105,520	(25,198)
Taxation	11	-	-	-	-	-	-
Transfer between funds	21	80,905	(80,905)	-	34,593	(34,593)	-
Net movement in funds for financial year	21	(17,777)	(90,316)	(108,093)	(96,225)	71,027	(25,198)
Total funds brought forward	21	104,182	1,467,409	1,571,591	200,406	1,396,381	1,596,786
Total funds carried forward	21	86,405	1,377,093	1,463,498	104,182	1,467,409	1,571,591

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 39 to 54 form part of these financial statements


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

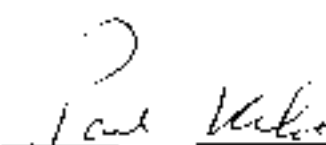
**BALANCE SHEET
AS AT 31 DECEMBER 2022**

	Note	2022 €	2021 €
Fixed Assets			
Tangible assets	14	139,666	149,021
Current Assets			
Short-term investments	15	360,000	360,000
Debtors	16	149,693	129,404
Cash at bank and in hand	17	1,001,805	1,084,814
		1,511,498	1,574,218
Current Liabilities			
Creditors: Amounts falling due within one year	18	(187,666)	(151,648)
Net Current Assets		1,323,832	1,422,570
TOTAL NET ASSETS		1,463,498	1,571,591
FUNDS OF THE CHARITY:			
Restricted funds	21	86,405	104,180
Unrestricted funds			
- Operational Reserve	21	942,000	929,387
- Designated funds	21	435,093	538,022
TOTAL FUNDS		1,463,498	1,571,591

The notes on pages 39 to 54 form part of these financial statements.

The financial statements were approved and authorised for issue by the Board of Directors on the 23 May 2023 and signed on its behalf by


Cathy Greve
Director


Paul Kehne
Director

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

**STATEMENT OF CASH FLOWS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022**

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

	Note	2022 €	2021 €
Net (expenditure) for the year		(108,003)	(25,198)
<i>Adjustments for:</i>			
Depreciation	14	29,199	34,890
(Increase)/ decrease in debtors		(20,280)	62,012
Increase/ (decrease) in creditors		36,018	(29,697)
Net cash flows from operating activities		(63,165)	42,007
Cash flows from investing activities			
Purchase of tangible assets	14	(19,844)	(40,444)
Cash used in investing activities		(19,844)	(40,444)
Change in cash at bank and in hand during the year		(83,009)	1,563
Cash at bank or in hand at the beginning of the year		1,084,814	1,443,251
Cash and cash equivalents at end of year		1,001,805	1,084,814
Reconciliation to cash at bank and in hand:			
Cash at bank and in hand		1,001,805	1,084,814

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022**

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 31. 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 (SOFAs).

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.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

(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 in conditions within an agreement that have not been met and are not within the control of the charity at year end

7.3 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

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

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 cost 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

The carrying values of tangible assets are reviewed annually for impairment in periods 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.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

- 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 in note 1, 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.

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 Company makes estimates and assumptions concerning the future. The resulting accounting estimates will, by definition, seldom equal the related actual results. 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.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

(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 intangible assets and tangible assets during 2022.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

4. DONATIONS AND LEGACIES

	Restricted funds	Unrestricted funds	Total 2022	Total 2021
	€	€	€	€
Collections	-	64,758	64,758	-
Donations	10,919	116,546	127,465	151,787
Donations In Kind	12,520	-	12,520	7,563
Memberships	-	11,450	11,450	15,277
Legacies	-	7,755	7,755	101,500
	23,439	200,509	223,948	276,127

All income received is primarily from the Republic of Ireland. We received a restricted donation of €9,327 from Edwards Lifesciences International Fund (to support the future development of a scheme to provide seizure detection devices to service users) and an unrestricted donation of €457 from the Cisco Matching Donor Advised Fund through the Charities Aid Foundation (CAF) America.

The restricted donations include €9,327 from Edwards Lifesciences International fund, €1,080 In-Memory donation and €512 In-Memory corporate support. The amounts relating to In Memory income are included in the restricted fund balance carried forward of €47,644 (2021: €36,877). This relates to total funds raised in 2021 and 2022 specifically for the purpose of launching a new service in future years to provide wearable seizure-monitoring devices to service users as detailed in note 21.

In accordance with our policy on working with pharmaceutical & medical device industries, Epilepsy Ireland discloses all contributions from this sector. In 2022, we received the following contribution which is included in donations:

- Liva Nova: €3,000 support for the Annual Conference.

A non-cash amount of €11,500 (2021: €7,563) is included under Restricted Donations, representing a donated service from Havas Media Group in relation to the promotion of a public awareness campaign for International Epilepsy Day 2022.

A non-cash amount of €1,020 (2021: €0) is included under Restricted Donations, representing a donated prize from Turkish Airlines in relation to the Annual Members Raffle.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

5. INCOME FROM CHARITABLE ACTIVITIES

Grant Income			Restricted funds	Unrestricted funds	Total 2022	Total 2021
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	44,818
HSE	CHO 7	Service Agreement	483,997	-	483,997	483,997
HSE	CHO 8	Service Agreement	37,224	-	37,224	37,224
Pobal	Stability Fund	Non-pay costs	19,253	-	19,253	(10,253)
ATU Sligo	Specialised Training	Training For Success	37,389	-	37,389	109,004
Mayo Sligo Leitrim ETB	Specialised Training	Training For Success	53,601	-	53,601	-
Pobal	SSNO	Salary and assoc. costs (2 positions)	75,037	-	75,037	78,068
Slaintecare	Integration Fund	Service Delivery	-	-	-	11,415
Other Grants	Co. Council Grants	Purchase of equipment	2,101	-	2,101	6,810
			937,529		937,529	935,197
Non-Grant Income						
BM Training Programme			-	166,792	166,792	151,050
Other Income Generating Services			(2,000)	7,404	5,404	6,311
			(2,000)	174,196	172,196	157,361
Total			935,529	174,196	1,109,725	1,092,558

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 2022	Total 2021
	€	€	€	€
Raffles and Lotteries	23,376	12,750	36,126	45,601
Campaigns and Appeals		12,260	12,260	18,030
Fundraising Events	9,482	113,882	123,364	85,249
	32,858	138,892	171,750	148,880

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

7. INVESTMENT INCOME

	Restricted funds	Unrestricted funds	Total 2022	Total 2021
	€	€	€	€
Interest Income		2,375	2,375	2,015
		<u>2,375</u>	<u>2,375</u>	<u>2,015</u>

8. OTHER INCOME

	Restricted funds	Unrestricted funds	Total 2022	Total 2021
	€	€	€	€
Miscellaneous Income		22,242	22,242	17,800
	<u>0</u>	<u>22,242</u>	<u>22,242</u>	<u>17,800</u>

9(a). EXPENDITURE ON CHARITABLE ACTIVITIES

Activities Undertaken Directly	Grant funding of activities	Support costs [Note 9(b)]	Total 2022	Total 2021
€	€	€	€	€
Activity				
Information & support	127,017	-	664,712	661,344
Training & education	69,351	-	348,609	331,805
Awareness	61,032	-	201,915	160,664
Advocacy	354	-	101,407	118,918
Research	1,443	83,850	109,545	68,878
	<u>259,208</u>	<u>83,850</u>	<u>1,426,188</u>	<u>1,341,609</u>

	Restricted funds	Unrestricted funds	Total 2022	Total 2021
	€	€	€	€
Activity				
Information & support	539,356	125,356	664,712	661,344
Training & education	284,905	63,703	348,609	331,805
Awareness	133,962	67,953	201,915	160,664
Advocacy	77,950	23,457	101,407	118,918
Research	29,061	80,484	109,545	68,878
	<u>1,065,234</u>	<u>360,954</u>	<u>1,426,188</u>	<u>1,341,609</u>

Awareness includes a non-cash donated service from Havas Media Group in relation to the promotion of a public awareness campaign for International Epilepsy Day 2021 and 2022 (See Note 4).

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

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

Charitable activities Charge for financial year	2022 €	2021 €	Basis of allocations
Governance costs	40,893	46,441	No. Activities
Wages & Salaries	865,715	871,724	Direct costs
Information Technology	13,422	16,359	No. Activities
Travel & Subsistence	37,904	15,535	Direct costs
Rent and Building maint. services	62,144	58,613	Direct cost
Office Expenses	33,852	51,278	Direct cost
Depreciation	29,199	34,890	
Total	1,083,129	1,094,840	

10(a). EXPENDITURE ON RAISING FUNDS

Activities Undertaken Directly	Support costs (Note 10(b))	Total 2022	Total 2021
€	€	€	€
Expenditure on raising funds	43,543	211,945	215,969
	43,543	211,945	215,969

	Restricted funds	Unrestricted funds	Total 2022	Total 2021
	€	€	€	€
Raising donations, legacies, corporate donations & regular giving	11,276	-	11,276	15,100
Fundraising activities – campaigns, appeals and events	12,935	19,332	32,267	39,081
Support costs (Note 10(b))	1,063	167,339	168,402	161,788
	25,274	186,671	211,945	215,969

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

Fundraising activities Charge for financial year	2022 €	2021 €	Basis of allocations
Governance costs	6,761	3,275	No. Activities
Wages & Salaries	149,097	161,788	Direct cost
Information Technology	2,064	-	No. Activities
Travel & Subsistence	5,807	8,856	Direct cost
Office Expenses	4,673	5,494	Direct cost
Total	168,402	179,413	

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

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

	2022	2021
Average number of persons employed	22	25
Service delivery	12	14
Fundraising	4	5
Administration	3	3
Training	3	3
	22	25

The staff costs comprise:

	€	€
Information & Support	333,822	343,881
Training & Education	195,000	190,730
Awareness	91,768	91,012
Advocacy	95,570	89,171
Research	17,956	17,946
Administration	127,543	135,471
Fundraising	148,353	162,280
Other Compensation Costs	4,801	4,167
	1,014,813	1,034,668

Included in the above are costs as follows:

Employer's PRSI	93,337	96,055
Contributions to pension scheme (Note 23)	54,539	57,426

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

	2022	2021
€60,001 - €70,000	1	1
€70,001 - €80,000	-	-
€80,001 - €90,000	1	1

The total remuneration for key management personnel for the financial year amounted to €187,597 (2021: €186,417). Remuneration included salaries, employer PRSI and pension contributions

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

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

Directors' remuneration and transactions:

No remuneration or other benefits have been paid or are payable to any directors from the funds of the charity during the year. Reimbursement for vouched expenditure of €58 was paid during the financial year.

13. NET (EXPENDITURE)/INCOME

	2022	2021
	€	€
The net expenditure for the financial year is arrived at after charging:		
Directors' remuneration and emoluments	-	
Operating Lease	31,410	23,604
Depreciation	29,199	34,890
Auditors' remuneration for external audit services	17,270	17,927
Bank deposit interest	(2,015)	(3,453)

14. FIXED ASSETS

	Premises	Fixtures & Fittings	Computers & Equipment	Total
	€	€	€	€
Cost				
At 1 January 2022	122,470	60,539	104,470	287,479
Additions	-	2,550	17,794	19,844
At 31 December 2022	<u>122,470</u>	<u>63,089</u>	<u>121,764</u>	<u>307,323</u>
Depreciation				
At 1 January 2022	17,600	48,739	72,119	138,458
Charge for during the year	<u>1,775</u>	<u>6,091</u>	<u>21,883</u>	<u>29,199</u>
At 31 December 2022	<u>18,825</u>	<u>54,831</u>	<u>94,002</u>	<u>167,657</u>
Net book value				
At 31 December 2022	<u>103,645</u>	<u>8,258</u>	<u>27,762</u>	<u>139,666</u>
At 31 December 2021	<u>104,870</u>	<u>11,800</u>	<u>32,351</u>	<u>149,021</u>

15. SHORT-TERM INVESTMENTS

	2022	2021
	€	€
Short-term investments	360,000	360,000

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

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

16. **DEBTORS:** Amounts falling due within one year

	2022	2021
	€	€
Trade Debtors	94,562	76,899
Prepayments	79,154	37,233
Other Debtors	25,977	15,272
	<u>149,693</u>	<u>129,404</u>

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

17. **CASH AT BANK AND IN HAND**

	2022	2021
	€	€
Cash at bank and in hand	1,001,805	1,084,814
	<u>1,001,805</u>	<u>1,084,814</u>

18. **CREDITORS:** Amounts falling due within one year

	2022	2021
	€	€
Trade Creditors	72,853	39,433
Accruals	53,932	29,822
Deferred Income	40,735	41,363
PAYC/PRSI/USC	19,846	21,777
Other Creditors	300	15,253
	<u>187,666</u>	<u>151,648</u>

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

19. **DEFERRED INCOME**

	2022	2021
	€	€
Balance at beginning of year	41,363	42,937
Amount received during the year	40,735	41,363
Amount released to SOFA during the year	(41,363)	(42,937)
Balance at end of year	<u>40,735</u>	<u>41,363</u>

The deferred income at the end of the year relates to HSE CHOT Income relating to 2023 invoiced in 2022.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

20. FINANCIAL INSTRUMENTS

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

	2022	2021
	€	€
Financial assets		
<i>Measured at undiscounted amounts receivable</i>		
• Debtors (Note 16)	149,693	179,404
Financial liabilities		
<i>Measured at undiscounted amount payable</i>		
• Creditors (excluding deferred income and PAYE/PRSI/USC) (Note 16)	127,085	88,508

21. ANALYSIS OF FUNDS

	Opening balance 01-Jan 2022 €	Income €	Expenditure €	Transfers €	Closing balance 31-Dec 2022 €
Restricted Funds					
Health Service Executive	11,476	750,148	(804,872)	53,123	9,875
DRCD Covid Stability Fund	7,475	19,253	(26,728)	-	-
The Community Foundation	8,101	-	(4,050)	-	4,051
SSND Funding (Pobal)	9,409	75,017	(84,446)	0	-
Mayo Sligo Leitrim ETB	-	53,601	(57,709)	4,108	-
ATU Sligo	-	37,389	(61,063)	23,674	-
SainteCare Implementation Fund	1,204	-	(1,204)	-	-
Havas (in-kind donation)	-	11,500	(11,500)	-	-
Turkish Airlines (in-kind donation)	-	1,020	(1,020)	-	-
In Memory Fundraising	36,827	11,073	(756)	-	47,644
Research funding	-	23,376	(23,376)	-	-
Other Grants	29,690	9,420	(14,284)	-	24,835
	104,182	991,826	(1,090,508)	80,905	86,405

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

Unrestricted funds					
Operational Reserve	929,387	538,214	(144,696)	180,905	942,000
Designated Funds					
- Premises reserve	100,000	-	-	-	100,000
- Research Provision	188,022	-	(73,411)	-	114,611
- Awareness Campaigns	100,000	-	(29,518)	-	70,482
- Aids and Appliances	50,000	-	-	-	50,000
- Strategic Plan Implementation	100,000	-	-	-	100,000
	<u>538,022</u>	<u>-</u>	<u>(102,929)</u>	<u>-</u>	<u>435,093</u>
Total Funds	1,571,591	1,530,040	(1,638,133)	-	1,463,498

HSE-funded services are only partially funded and €53,123 (2021: €34,592) has been transferred from the unrestricted Operational Reserve to meet the full cost of providing the services.

€0.875 of HSE funds (2021: €11,476) is made up of National Lottery grants and are being carried forward for use in 2023.

The balances on the Community Foundation (€4,050) relate to depreciation charges to be incurred in future years.

Other restricted grants totalling €9,427 (2021: €29,690) are also carried forward to be utilised in 2023. The In Memory fundraising balance carried forward of €47,644 (2021: €36,827) relates to total funds raised in 2021 and 2022 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 2022, the Research reserve was reduced by €73,411 to meet the cost of current research grants in the year. The Awareness reserve was reduced by €29,518, costs associated with the 2022 International Epilepsy Day campaign.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	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>

In respect of prior year

	Restricted funds	Unrestricted funds	Closing Balance
	€	€	€
Fixed Assets	-	149,021	149,021
Current Assets	104,182	1,470,036	1,574,218
Liabilities	-	(151,648)	(151,648)
	<u>104,182</u>	<u>1,467,409</u>	<u>1,571,591</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, €54,530 (2021: €57,426) is charged to the Statement of Financial Activities in the financial year in which it arises. There was €0,492 payable at the financial year-end (2021: €8,681).

24. CONSTITUTION

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

25. COMMITMENTS

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

	2022	2021
	€	€
Within one year	111,583	15,178
Between two and five years	<u>62,454</u>	-
Total	<u>174,037</u>	<u>15,178</u>

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2022**

Operating Lease Commitments

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

	2022	2021
	€	€
Within one year	78,950	31,110
Between one and two years	<u>25,470</u>	<u>33,875</u>
Total	54,470	65,285

26. RELATED PARTY TRANSACTIONS

Other than as set out in Note 12 (remuneration of key management personnel and reimbursement of vouched expenditure by the Directors), there were no related party transactions during the current or previous financial year.

27. SUBSEQUENT EVENTS

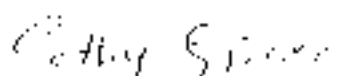
There are no significant events subsequent to the financial year end.


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 23 May 2023.


Cathy Grieve
Director


Paul Kehoe
Director