



ANNUAL REPORT 2023

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Our Vision

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

Our Mission

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.

Our Values

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

Our Strategic Plan 2022 - 2026 is centred around six key strategic aims, which are as follows:

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

This annual report for 2023 will set out how we have worked towards our vision through these six strategic aims.

We confirm that Epilepsy Ireland complies with the Charities Governance Code. As a charity seeking donations from the public, we aim to comply with the Guidelines for Charitable Organisations on Fundraising from the Public. Epilepsy Ireland is Triple Locked. Triple Lock status is awarded by the Charities Institute of Ireland to charities that uphold the highest standards in transparent reporting, ethical fundraising and strong governance structures. This recognition is the gold standard for Irish charities to offer assurances to donors, members, and the general public. Epilepsy Ireland also holds "Improving Quality" (IQ) quality standard since September 2021. Improving Quality (IQ) is a quality system developed specifically for small to medium-sized Community and Voluntary Sector Organisations.



OUR PEOPLE

Board of Directors

Ms Cathy Grieve (Chairperson)
Ms Clare O'Dea (Secretary)
Mr Paul Kehoe (Treasurer)
Ms Helen Behan
Mr Aaron Chalke
Mr Mark Curran
Mr Paul Fahey
Ms Mary Fitzsimons
Mr Ambrose Kealy
Dr Anne Kilroy
Prof Mary King
Ms Anne Maguire
Ms Nicola Nagle
Ms Nicola Saarsteiner

Finance & Audit sub-committee

Ms Cathy Grieve
Mr Paul Kehoe
Mr Paul Fahey
Mr Owen McCarthy
Mr Allan Barrett
Ms Caoimhe Neary
Mr Liam Woulfe

Quality & Safety sub-committee

Dr Anne Kilroy
Mr Ambrose Kealy
Ms Mary Fitzsimons

Nominations & Governance sub-committee

Ms Helen Behan
Ms Clare O'Dea
Ms Cathy Grieve
Mr Mark Curran

Remuneration sub-committee

Ms Cathy Grieve
Mr Paul Kehoe
Ms Clare O'Dea

Research sub-committee

Prof Mary King
Ms Mary Fitzsimons
Mr Paul Kehoe
Ms Anne Maguire

Communications & Fundraising sub-committee

Mr Aaron Chalke
Ms Nicola Saarsteiner
Mr Tony Caravousanos

STAFF

Chief Executive

Peter Murphy

SERVICES

Director of Services

Tara Smith

National Information Officer

Geraldine Dunne

Community Resource Officers

Carina Fitzgerald (Eastern Region)
Agnieszka Polak (Eastern Region)
Cliona Molloy (Midlands Region)
Joanne Lynch (South East Region)
Sharon O'Connell (Southern Region, Cork)
Niamh Jones (Southern Region, Cork)
Pam O'Brien (Southern Region, Kerry)
Margaret Dixon (Mid West Region)
Catherine Caffrey (West Region)
Agnes Mooney (North West Region)
Mary Baker (North East Region)
Catherine Gleeson (National Cover)
Cian O'Regan (Youth Resource Officer)

Epilepsy Specialist Nurse

Sinead Murphy, RANP (Beaumont Hospital)

Training & Quality Manager

Edel Curran

Training & Education Officer

Maire Tansey

FUNDRAISING, COMMUNICATIONS AND ADMINISTRATION

Advocacy & Communications Manager

Paddy McGeoghegan

Fundraising & Development Manager

Cian Dikker

Membership & Fundraising Officer

Ashley Butler

Churchgate Collections Co-ordinator

Barbara Doyle

Fundraising & Development Executive

Roisin Dolan

Finance Manager

Deirdre Noyes

Executive Assistant

Catherine Powell

Reception & Administration

Sophie Williams

A MESSAGE FROM OUR CHAIRPERSON AND CEO



Cathy Grieve, Chairperson



Peter Murphy, CEO

Welcome to Epilepsy Ireland's Annual Report for 2023, the second year of our 2022-2026 Strategic Plan. We have listened to the many voices of the epilepsy community, and we now carry from the past to the present and into the future. For over 50 years Epilepsy Ireland has provided authoritative and very necessary help to the epilepsy family, and our influence and impact has been expansive and significant. Despite progress in many areas, there is still work to do in educating, informing and improving awareness. These still pose some tough challenges, but we will endure, and we won't let anything get in our way.

During consultations for our Strategic Plan the need for more services for young people with epilepsy was clearly identified and communicated to us. Therefore, implementing new programmes for this age group has been high on our priority list. During 2023, there have been several new service developments targeted at young people living with epilepsy which you will read about in this report.

As a board, we are delighted to see these new developments and are excited by plans to further expand on this in 2024 with the hope that increasing supports for young people with epilepsy will enable them to reach their full potential.

Perhaps the best example of our influence and impact in 2023 was the success of our Free Travel campaign for those unable to drive because of their epilepsy. After some trojan advocacy work by everyone associated with Epilepsy Ireland, as part of Budget 2024, the Minister for Social Protection Heather Humphreys TD agreed to introduce Free Travel for those deemed medically unfit to drive for at least a year and those who have never been able to drive due to their epilepsy. As I write this, applications for the new scheme have just been opened in what is a proud moment for the organisation – more details on www.epilepsy.ie.

Keeping with best Board practice, we have rotation of members each year, some leaving and others joining. I would like to thank all my fellow board members for their commitment, time, and support in 2023, in particular those who stood down during the year – Mark Dowdall, Shane O'Brien and Derry Gray. I would also like to thank our CEO, Peter Murphy and all the staff for their ongoing commitment and dedication.

Most importantly, I would like to end this foreword by thanking every person who supported the work of Epilepsy Ireland in 2023 – it is greatly appreciated and so important as we continue our work towards a society where no person's life is limited by epilepsy.

Thank you and I hope you will enjoy reading about our activities throughout 2023.

As we look back on 2023, it is a year that everyone connected with Epilepsy Ireland can be immensely proud of, with many highlights across what was an extraordinarily busy year.

Perhaps the biggest of those was the hosting of the International Epilepsy Congress in Ireland for the first time since 1997. At the Congress, the Taoiseach paid tribute to the work of Epilepsy Ireland and our history in working with government for the betterment of people with epilepsy and their families. To have such a glowing acknowledgement from the head of Government in front of the global epilepsy community was a fantastic moment for everyone associated with the work of Epilepsy Ireland.

In this report, you will read about our contributions to this global event for the international epilepsy community and the legacy that we hope that will be continued as it travels the globe.

It was also a watershed year for some of our most longstanding advocacy campaigns – showing the grit and determination of all involved in the organisation, including our members and service users, to help achieve positive policy changes for people with epilepsy. While considerable progress has been made, we know that there is much more to do. With several elections on the horizon, we look forward to working with people with epilepsy and their families to campaign for more positive policy changes in the years ahead.

2023 also saw our investment in research since 2009 surpass the €1.5 million mark – a sizeable total investment for an organisation of our size. We certainly hope to be hitting the next marker of €2m in the not-too-distant future!

These highlights and more you will read about in the following pages come at a time when we continue to experience high demand for our essential support and education services, with just under 20,000 contacts with our team over the course of 2023. There were several new developments in our programmes in 2023, and excitingly, there are more new initiatives on the way! Financially, it was also a positive year for the organisation and strong fundraising performance helped pave the way for continued investments in our strategic priorities in the years ahead.

The work outlined in this report would not have been possible without you – our dedicated members, supporters, and volunteers – highlighting how it is only by working together that we can achieve a society where no person's life is limited by epilepsy. On behalf of everyone at Epilepsy Ireland, thank you for your support and we hope you will continue to be alongside us in 2024.

SUPPORT AND EDUCATION

Empower people with epilepsy through support and education.

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 epilepsy. Our services aim to empower people with epilepsy and their families at all stages of their journey with the condition. Our work also extends to health professionals, schools, employers, and the public.

Contacts

Our services continued to experience high demand in 2023, with a total of 19,975 contacts across the year (2022: 19,917). This includes 9,533 individual contacts via phone, email, zoom or in-person meetings (2022: 10,463) while 10,442 attended our range of group activities that are offered throughout the year (2022: 9,454).

Registered ANP

As noted, Epilepsy Ireland fund a Registered Advanced Nurse Practitioner (RANP) post at Beaumont Hospital. The RANP also provides clinics in the National Maternity Hospital, the Rotunda, the Coombe and Our Lady of Lourdes Hospital in Drogheda. Included in individual contacts is 1,111 contacts with the RANP in 2023 (2022: 1,334). In addition to this, the RANP provides specialised support for our services team, co-delivers online epilepsy education sessions alongside our Community Resource Officer team and contributes to the review and updating of our information materials. Wider aspects of the RANP's work in 2023 included the hosting of a special event focussed on Women with epilepsy and the Menopause and the initiation of the Epilepsy Journal Club; a club where clinicians present latest epilepsy research and discuss with colleagues from across the country - including the Epilepsy Ireland team.

Training for Success

2023 saw the conclusion of Training for Success, which has been part of our service for the last 25 years. 'Training for Success' first began in 1998 and was specifically targeted at people living with epilepsy whose education or employment prospects may have been impacted by their condition. The course offered participants an opportunity to develop their skills for entry into the workforce or further education – skills which may not have been developed fully due to their epilepsy – for example, due to frequent hospital visits for teens during their secondary school years. The course found its home in IT Sligo, now Atlantic Technological University

Sligo, and grew to become a QQI Level 5 accredited course which acted as a springboard for so many people with epilepsy.

While it was difficult to say goodbye to Training for Success, the environment we live in now is much different to that of 1998. There is now an abundance of different adult learning education courses available across the country; and while there is still work to be done, there is a much more inclusive structure in third level institutions which can help assist people with epilepsy to pursue their chosen course. In addition, attitudes to epilepsy have shifted dramatically over the past two decades.

These societal changes and availability of a wider array of courses has seen interest in Training for Success falling over the last number of years. In addition, recent changes with IT Sligo becoming a Technological University would have seen the course change significantly, losing some of its most unique aspects. While it was ultimately a difficult decision, we are confident this was the correct decision and remain proud of the positive impact the course had in people's lives.

Living Well with Epilepsy Programme

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 2023, 233 individuals availed of the Living Well with Epilepsy Programme (2022: 365).

Supports in the Wider Community

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 Resource for Pre-schools, Schools, and Colleges' and our 'Epilepsy in the Workplace' guide.

Alongside this, we also provide epilepsy awareness presentations for schools, medical institutions, workplaces and other settings where a need is recognised.

In 2023, we delivered a total of 152 talks to schools, preschools, and other education settings with 3,731 people attending (2022: 119; 3,271).



Our Community Resource Officer Agnieszka Polak with the Living Well with Epilepsy Programme.

New Service Developments

Following on from the introduction of several new offerings in 2022, this continued in 2023 with a particular focus on increasing our engagement with young people/children with epilepsy and their family members.

New developments included 'Teen Time', our Young Adult Meet-Up and Creative workshops for siblings of children with epilepsy. A short synopsis of each of these events is included below, with all are set to continue across 2024.

Teen Time

From our years of serving the epilepsy community, we've heard from now-adults about how they never knew anyone with epilepsy growing up and many feel that they would have benefited in later years from being more comfortable about discussing their epilepsy from an earlier age with those around them. This is why we established 'Teen Time'. This online event aims at bringing young people with epilepsy from across Ireland together in a safe environment where they can either discuss their own personal journey with epilepsy with others who know what they're going through.

Young Adult Meet-Up

Young adulthood can be a challenging time for those living with epilepsy. People living with the condition can be facing exams; experiencing increased independence for the first time; starting out in their careers; or building new relationships. The natural stresses, anxiety, expectations, and excitement that this can bring, can have a knock-on effect on a person's epilepsy. This group enables attendees to meet with others of a similar age who are living with epilepsy and allows them to discuss their epilepsy and any new challenges that they may be experiencing as a result of young adulthood. It also provides attendees with an opportunity to hear from others who are also navigating or have already navigated these challenges and learn from these shared experiences.

Workshop for Siblings of Children with epilepsy

When parents/guardians are caring for and supporting a child with epilepsy - particularly where the condition is complex - there can be a knock-on impact for that child's young siblings. Due to the challenges that epilepsy can bring, siblings can sometimes feel isolated or feel worried about their loved one's condition. The workshop allows children of siblings with epilepsy to participate in online fun, games, and discussion - with other children who also have a sibling with epilepsy. Through this, they will not only have fun but also have an opportunity to discuss concerns they might have about their sibling's long-term health condition - alongside other children in a similar situation to them. This can help a child feel less isolated and concerned about their sibling's epilepsy, and help to increase their understanding of epilepsy as a whole.

EpiLearn

Another significant service development was the launch of EpiLearn, our organisation's first foray into the world of e-learning during National Epilepsy Week in May. The app was developed in collaboration with healthcare eLearning specialists, Aurion Learning, using their latest learning platform, ByteKast and is available in Apple, Android and desktop formats. It complements existing support services and information resources by adding a new digital, interactive layer for those seeking to learn more about epilepsy. The



Our Community Resource Officer for Kerry, Pam, revealed her hidden face-painting skills at our Annual family fun day!

app provides bitesize information on epilepsy, structured into pathways of learning that features videos, quizzes, and practical exercises. The app was launched with one pathway, designed to give users an introduction to epilepsy and features four distinct levels focussed on understanding epilepsy, seizure types, seizure triggers, medications and seizure safety. We look forward to building new resources within the app in 2024.

Special Events

In September, the International Epilepsy Congress came to Dublin and working with our colleagues in the International Bureau for Epilepsy and International League Against Epilepsy, we hosted a special event as part of the congress, which replaced our National Conference for 2023. More on this event can be found within the *Collaboration, Care and Knowledge* section on page 9 of this Annual Report.

Our annual Family Fun Day took place in July, with Fota Island Wildlife Park being the destination this year. The fun day allows families and children with epilepsy come together in a fun environment to meet each other.

Other special events held in 2023 include:

- Life-Balance and Self-Care on your journey with epilepsy
- Employment Rights and Job Search Tips
- Memory and Study Skills for Teens with Epilpsy
- Epilepsy and Menopause – A special event for women with epilepsy
- Seizure Detection Devices – The need to know

Using our relationships with the medical community and contacts within the community, we will continue to host special 'themed' events throughout 2024.



We were pleased to support the important National Campaign around menopause by hosting a special event for women with epilepsy.

MEMBERSHIP AND ENGAGEMENT

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

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

Service-User Consultation Group

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

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

Service-User Survey

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

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

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

Volunteers of the Year

The Volunteer of the Year award is a small token of appreciation of the outstanding efforts an individual or a group of individuals have undertaken in support of Epilepsy Ireland and highlights the importance of volunteering within our organisation. In 2023, there were two recipients of the volunteer of the year award – Mark McGuire from Co. Kildare and Rachel Langan from Co. Galway. Mark was recognised for his incredible fundraising and awareness efforts for Epilepsy Ireland, scaling Kilmanjaro in the name of his son Ciáran who was diagnosed with epilepsy in 2021 while Rachel

was recognised for her advocacy work in raising the issue around deferred examinations for Leaving Cert students who experience seizures during their exams. We are proud to call Mark & Rachel our volunteers of the year!



Our volunteers of the year, Rachel & Mark

International Youth Summit & Golden Light

As part of the activities for the International Epilepsy Congress, a special international Youth Summit for young people with epilepsy was arranged by our colleagues in the International Bureau for Epilepsy. The summit brought together inspiring young people with epilepsy, from all over the world – including Epilepsy Ireland volunteers. The event not only highlighted the challenges faced by young people living with epilepsy but also provided a platform for them to share their experiences, knowledge, and advocate for a better future. While we're obviously biased – we were so proud of the contributions made by our delegates Jack, Cara, Lucy, Melissa, Jonathon, Sophie, Grace, and Rachel at the summit.

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



Team Epilepsy Ireland at the Youth Summit!

COLLABORATION, CARE AND KNOWLEDGE

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.

Buccal Midazolam Training for Professionals and parents

Since 2009, Epilepsy Ireland has been providing a training programme in Epilepsy Awareness & the Administration of Buccal Midazolam (BM) to health and allied health professionals. Trainees include healthcare workers, education staff like teachers and SNAs, bus escorts, employers/employees (working alongside a person with epilepsy), community workers, facilitators of extra-curricular activities in the community and more. 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. 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 team and Community Resource Officers. The programme has grown exponentially over the years and has become a core part of our work at Epilepsy Ireland. In 2023, 2,791 professionals took part in this important training through 214 training sessions (2022: 2,536; 236).

Epilepsy Ireland's Community Resource Officers also deliver Buccal Midazolam (BM) Rescue Medication 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 2023, 39 individual courses were delivered by our team with 183 parents/carers attending. (2022: 55; 171)

Investing in Epilepsy Research

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

In 2023, one new project was supported. To date, no study has examined the health information needs of women with epilepsy and their families from preconception through to postpartum in Ireland. The study we have invested in will change that and we believe it has the potential to make a huge impact on the future care of women with epilepsy in Ireland, who are planning pregnancies in the future - as the project will also work to develop new evidence-based resources to support women and health professionals during this period.

The project is entitled 'Health information and education resources for women with epilepsy from preconception

to postpartum' and is being led by Dr. Aisling Walsh of the Department of Public Health and Epidemiology at the Royal College of Surgeons Ireland. Dr. Walsh will be supported by an extensive research team, all with expertise in supporting women with epilepsy – both in a research and clinical setting. The study is funded by the Health Research Board (HRB) under the Applied Partnership Awards 2022 and will see a €174,609 investment across 2 years, of which €15,000 is provided by Epilepsy Ireland. Co-funding of €15,000 is also provided by the HSE's National Women and Infants Health Programme.

Alongside this investment, our continued investment in previously supported studies continued, including:

- miR-CDD: Molecular mechanisms, therapeutic targets and biomarkers for CDKL5 Deficiency Disorder (CDD); led by Dr Omar Mamad & Erva Ghani (RCSI).
- Circadian biomarkers in pre-clinical and clinical Dravet Syndrome; led by Dr Cristina Reschke & Radharani Benvenuti (RCSI).
- EPIVIEWS: Exploring Patient Impact & Value in Epilepsy Wearables for Seizure Monitoring; led by Prof Rob Argent & John David Dalameiro (RCSI).
- Predicting and monitoring outcomes in Autoimmune Encephalitis (POTA): Principal Investigator - Prof. Norman Delanty, RCSI.
- Long non-coding RNAs: regulators of epileptogenesis and potential targets for therapy; Principal Investigator - Dr Gary Brennan, UCD.
- Epilepsy Mortality in Ireland; led by Dr Yvonne Langan; St James's Hospital/Trinity College in collaboration with the Health Research Board.
- Development of a non-invasive ultrasound stimulation approach to modulate the seizure-like firing of induced pluripotent stem cell-derived neurons from epileptic patients; led by Dr. James Britton, Department of Physiology NUI Galway.

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

To learn more about our investment in research, visit the 'Research' section of www.epilepsy.ie.

Increasing awareness of SUDEP and epilepsy-related 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. 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 and risk can be minimised by avoiding seizure triggers, avoiding alcohol, and adhering

to medication regimes. SUDEP Action Day is one of the most important days in our calendar to raise awareness of SUDEP amongst the entire epilepsy community, including healthcare professionals. In October 2023, we shared personal testimonies from families who had lost a loved one due to SUDEP. We also undertook a patient facing survey, seeking to learn more about knowledge of SUDEP among people with epilepsy (and parents of children with epilepsy) and about communications between them and their healthcare team on SUDEP. 82% of respondents believed that SUDEP should be discussed with people with epilepsy by medical professionals regardless of whether they are deemed at high risk or not while 50% believed that SUDEP should be discussed immediately on diagnosis; while 34% believed it should be discussed within 1 year of diagnosis. These findings alongside the many other findings within the survey will be crucial to our plans to build a national campaign to reduce epilepsy-related deaths in Ireland and we look forward to continuing this work in 2024.

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

Preparatory work also continued with SUDEP Action in 2023 for the introduction of the SUDEP Checklist in Ireland. The Checklist supports clinicians discussing epilepsy risks with patients and our work on introducing the checklist in Ireland has been made possible thanks to the fundraising efforts of the Cycle for Shane in 2022. Work will continue on this important project in 2024.

Other areas of Collaboration

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

- Six Joint Epilepsy Education Sessions for adults with a new diagnosis of epilepsy were co-delivered by Epilepsy Ireland CROs and HSE Advanced Nurse Practitioners. These events have proven to be a successful model of collaboration between EI and HSE professionals, and in 2023, we expanded the idea to provide two similar events for parents of children with new diagnoses.
- Working closely with the Irish Epilepsy League on advocacy issues including free travel and deferred exams
- Collaboration with international organisations such as SUDEP Action, Infantile Spasms Awareness Network and Epilepsy Advocacy Europe on specific campaigns and with a variety of national organisations including the Disability Federation of Ireland, the Neurological Alliance of Ireland, OACS Ireland and many others.

- We continued work with the Department of General Practice at UCC on developing a Consultation Guide for people with epilepsy and GPs designed to improve the patient experience at GP appointments.
- Participation in the HPRA's patient forum and the Department of Health's Valproate Stakeholder Group.

International Epilepsy Congress

One of the highlights for Epilepsy Ireland in 2023 was the holding of the International Epilepsy Congress in Dublin. The Congress is the largest international scientific epilepsy meeting, and over 3,000 healthcare and scientific professionals from across the global epilepsy community were in attendance to share expertise and knowledge with their colleagues.

The congress is organised every two years by our colleagues in the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). Not only did Epilepsy Ireland play a leading role in the organisation of the main congress, but we also led on the organisation of the first-ever public facing events associated with this huge international event for the entire epilepsy community, collaborating with both the IBE and the ILAE to make these possible. Historically, the congress was for scientific and medical professionals exclusively, but our events brought the congress directly to people with epilepsy and their families. This brought internationally renowned epilepsy experts directly to patients with epilepsy in Ireland – with our speakers delivering “plain-English” versions of their presentations from the main congress. Close to 400 people attended in-person across two nights, with approximately 300 people tuning in online each night. Topics discussed included:

- Climate Change & Epilepsy
- Ketogenic diet and beyond: what is on the horizon?
- Managing the challenge of anxiety in epilepsy
- Precision therapies for epilepsy
- The genetics of epilepsy in 2023
- The relationship between sleep & epilepsy
- Seizure detection systems & devices
- The cannabinoid story – what we have learned
- Complex and Rare Epilepsies
- Neuropsychological Interventions in newly diagnosed epilepsy
- The role of exercise in managing epilepsy
- When should surgery be considered?

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



The first-ever public events associated with the International Epilepsy Congress.

ADVOCACY, CAMPAIGNS AND COMMUNICATIONS

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

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.

Advocacy

2023 was a landmark year with some of our most longstanding advocacy campaigns successfully concluded. This includes key wins in the areas of deferred exams, free travel and the establishment of an inquiry into the historical licencing and prescribing of Sodium Valproate.

Free Travel

As a result of a longstanding campaign by Epilepsy Ireland, from July 2024, people who are medically unfit to drive for at least a year will be able to apply for the free travel scheme. The changes being made will remove the barrier of having to be on a qualifying payment in order to access free travel. The announcement to make these changes came in Budget 2024 in October and followed continuing campaigning by Epilepsy Ireland to TDs and Senators; the Department of Social Protection; and the Minister responsible, Minister Heather Humphreys.

Throughout our engagement on this issue, Minister Humphreys was clear on the impact that this issue can have on people with epilepsy, and we are incredibly grateful that she supported our campaign and secured these new measures as part of Budget 24.

We look forward to continuing to work with the Minister and her Department to bring in these much-needed changes in July 2024, something that will not only benefit the epilepsy community, but others who live with long-term health conditions or disabilities.

Deferred Leaving Cert Exams

After considerable progress on this matter in 2022, this longstanding issue which impacted students with epilepsy for decades was effectively resolved in 2023. Due to the nature of epilepsy, over the decades, many students with epilepsy experienced seizures either during their exam or over the course of the exam period which meant they were unable to complete their exams to the best of their ability or had to miss one or more exams. This meant that students who were unable to complete their exam(s), had no other option but to repeat their exams the following year, and hope that a seizure did not strike again at the most inopportune of moments. In 2022, deferred exams were introduced but only made provision for students who may have a medical emergency (such as a seizure) before their exam. After further campaigning by Epilepsy Ireland following that announcement, in 2023 the new criteria for deferred exams announced by the State Examinations Commission were expanded to include students who experienced medical emergencies during their exams. In the lead up to this announcement, we had met with both the State Examinations Commission and the Minister for Education to advocate for this change.

This was an extremely welcome development for students with epilepsy sitting the Leaving Cert in 2023 and beyond, and will alleviate what for decades, was an unnecessary

additional worry at one of the most stressful periods of the young person's life.

Sodium Valproate Inquiry

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

With a Terms of Reference agreed for the inquiry and the Department of Health seeking a chair for the inquiry, at the end of 2023, Epilepsy Ireland adopted a different role in relation to the inquiry. With outstanding matters such as the appointment of a Chair, inquiry resourcing, and ensuring families are supported to take part in the inquiry effectively, it is vital that decisions on these specific matters, above all else, meet the needs of those most directly affected. Ultimately, those needs are best represented by the families themselves, and therefore OACS Ireland will be leading on these final steps in 2024.

We look forward to this long-awaited inquiry being officially established in 2024 and to engaging with the inquiry in due course.

Other Advocacy Work

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

Website and General Communications

In 2023, our epilepsy.ie website had just under 180,000 visits, showing its importance to the epilepsy community in finding information and support. Several new sections were added to the site over the year, including:

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

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

Our social media channels continue to be an important

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

In addition to the above, outbound communications continued in 2023 – including four editions of our members’ newsletter, ‘Epilepsy News’; our annual Research Bulletin; and our monthly Ezines. We continued to actively engage with the media on relevant news items, awareness campaigns and advocacy issues.

International Epilepsy Day

Our flagship public awareness campaign centres around International Epilepsy Day in February 2023, we aimed to build on the key seizure first-aid words of “Time, Safe, Stay”. The key message aimed to highlight how the public’s general knowledge needs to be expanded to include seizure first aid and our key words of Time, Safe, Stay.

The campaign was supported by a number of our media volunteers sharing their stories of the lived experience of epilepsy. Combined with paid advertising and organic reach, there were several highlights to our awareness raising activities associated with the campaign including:

- Vox pops were recorded with the general public, showing how seizure first aid was not part of their general knowledge.
- Audio adverts were ran on Today FM & Spotify.
- Key visuals were carried in the Irish Times and Irish Independent .
- The key message and personal features were covered in titles such as the Irish Examiner, the Irish Farmer’s Journal, Her.ie, Joe.ie and on Virgin Media news.
- For paid social media channel advertising, a total of 2.5 million impressions were achieved.
- A number of media volunteers appeared on key regional radio stations such as Highland Radio, Galway Bay FM and Midlands 103.

We would like to thank everyone who shared and supported the campaign to help increase knowledge of Time, Safe, Stay.

‘Stand Up’ Campaign

In September 2023, we had the opportunity to conduct a new awareness campaign when free advertising space became available. Again, the campaign aimed to promote awareness of seizure first aid and Time, Safe, Stay by asking the question “If I fall down, will you stand up?”

The eye-catching campaign featured two Epilepsy Ireland volunteers Paul and Lucy and encouraged everyone to visit our website to learn more about how to correctly respond to a seizure - and especially the key words of Time, Safe, Stay.

The campaign was featured in locations across Dublin and kindly supported by all wings of the National Transport Authority of Ireland (NTA), helping us reach a large group of people with this important message.

Thank you to both the NTA and our incredible volunteers for being part of this campaign. A special thank you to our colleagues in Connolly Partners who helped create the campaign and organise advertising sites, mainly on a pro-bono basis.

Other campaigns

Epilepsy Ireland also led on and promoted other awareness raising activities in 2023, including:

- **National Epilepsy Week**

The theme of the week was #EpilepsyMatters - there are so many things that matter to people with epilepsy, and that was why it was fantastic to have a mix of activities happening throughout #EpilepsyWeek 2023 - including a Dáil debate on our Free Travel campaign; the launch of our Epilearn app; and a fantastic video raising awareness of epilepsy from our media volunteer Cara.

- **SUDEP Action Day**

As noted in the Collaboration, Care and Knowledge section, SUDEP Action Day is one of the most important days in our calendar. With a small social media budget promoting information about SUDEP and the two personal stories we had received – Orla’s story about the loss of her brother Kieran, and Jenny’s story of the loss of her husband Noel – the campaign performed extremely well with over 20k visits to our website across October.

- **Infantile Spasms Awareness Week**

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



One of the billboards featuring Paul and Lucy who shared their story for Epilepsy Ireland in Dublin City Centre.



Paul, Christine and Harry, who shared their story for Infantile Spasms Awareness Week 2023.

FUNDRAISING & FUNDING

Increase and diversify income

Supporter and Volunteer led events

Like previous years, throughout 2023 we received incredible support from communities across Ireland. This support was vital to raise the necessary funds for our organisation to continue our journey towards a society where no person's life is limited by epilepsy.

Our supporters raised funds in many brilliant and creative ways throughout 2023. In August, Mark McGuire from Co. Kildare climbed Mt. Kilimanjaro in the name of his son Ciarán, raising €8,271. The Glennon family came together to take part in the VHI Women's Mini-Marathon in June, raising €5,430. Rachel Carway and her husband Padraig used their wedding day to raise funds by making a novel request of their wedding guests: to donate the price of a drink for the bride and groom to Epilepsy Ireland. They raised €1,450 for Epilepsy Ireland in memory of Brianna Lynch.

These are just three examples of the incredible support we have received but we would like to express our gratitude to all those who supported Epilepsy Ireland in 2023 – the work outlined in this report would not have been possible without you.

Total non-grant income raised in 2023 was €905,599 (2022: €593,597).

Diversifying Income

As part of our strategic plan, one of our key aims is to diversify our income. National and global challenges in recent years mean the need to seek and secure funding from diverse sources has never been clearer. Our team secured funding from several new sources in 2023. This included:

- A commitment from Angelini Pharma to support a vital new role in our organisation – a Youth Resource Officer –



Mark atop Kilimanjaro flying the flag for EI!



Andrea and Sophia Glennon, presenting the cheque of funds raised to our Fundraising and Development Manager, Cian Dikker.

for two years. The role will be recruited in 2024.

- Desitin committed to providing sponsorship towards our International Epilepsy Day campaign in 2024, helping free up fundraised income for the organisation's other activities in the year ahead.
- 2023 was the first year that Epilepsy Ireland organised a Facebook Challenge event, the 45 for Epilepsy Challenge. This exciting new initiative brought together dozens of supporters, who together raised over €9,000. This challenge format will be repeated in the coming years.

Throughout 2024, we will continue to identify and pursue new sources of income.

Legacy Income

In 2023 Epilepsy Ireland was very fortunate to receive several significant gifts through bequests. Over €200,000 was received, through gifts large and small, from supporters who thoughtfully included Epilepsy Ireland in their will. Gifts such as these make an invaluable contribution to the work of Epilepsy Ireland. If you would like to discuss making a bequest, please contact our Fundraising & Development Manager Cian Dikker, by emailing cdikker@epilepsy.ie.

Funding

Epilepsy Ireland's main source of funding is through seven Section 39 Service Level Agreements (SLAs) with HSE Community Healthcare Organisations (CHOs) across the country. These agreements totalling €750,148, plus one-off funding of €29,449 in 2023 (2022: €750,148) contribute to staffing and other costs related to our support and education services – but do not cover the costs of these services in full.

HSE funding cuts during the post-2008 recession have never been restored, and we have worked to minimise funding shortfalls over the past 15 years through cost control measures, securing funding from other sources (e.g. the Scheme to Support National Organisations) and by growing non-grant sources of income.

An important external development in 2023 was the agreement between the Government and trade unions to a pay increase of 8% for all Section 39 workers. Although details were not available on the implementation of the pay deal at year end, it is hoped that funds made available through the deal in 2024 will assist in retaining staff and ensuring that fair remuneration is maintained in the current economic climate.



Rachel & Podge who used their big day to raise funds for EI!

CAPACITY AND GOVERNANCE

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

Our Board

The Epilepsy Ireland board of directors is responsible for setting the direction and strategy of the organisation and for ensuring that it is effectively and responsibly governed. As of 31 December 2023, the board was comprised of 14 volunteer members, drawn from a variety of backgrounds, skillsets, and experiences. Eight board members have a direct personal connection to epilepsy (i.e., either they or a close family member lives with the condition), three are medical/scientific professionals and three provide specialist skills and knowledge required by the board.

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

- Monitored progress at each meeting against the agreed 2023 operational plan and budget.
- Reviewed and reconfirmed the organisation's full compliance with the Charities Regulator Governance Code.
- Reviewed and approved updates to almost 20 operational and governance policies & procedures per the agreed review schedule.
- Reviewed and agreed changes and movements in the organisation's designated reserves.
- Reviewed and approved proposals on staff salaries, with reference to available benchmarking data and available resources.
- Undertook an analysis of potential long-term cost-reduction measures and agreed follow-up actions.
- Conducted a review of the organisation's insurance policies.
- Agreed an update to the Board development plan.
- Agreed to discontinue the Training For Success programme at ATU Sligo from August 2023.
- Approved the recruitment of two new staff roles in 2024 within services and communications/ advocacy.
- Received departmental updates from management team in the areas of support services, training, fundraising and advocacy/communications.

Finance & Audit sub-committee

The Finance & Audit sub-committee assists and advises the Board on the organisation's finances, risk, investments & reserves, general business activities and strategic direction. It consists of a mixture of board members and independent external experts. In 2023, the committee met on seven occasions. It made recommendations on annual budgeting, risk management, financial controls, pay policy, cost reduction measures, epilepsy research investments and the use of reserves and deposits. It also received updates on fundraising and funding activities throughout the year.

Other sub-committees

Other sub-committees of our board include:

- Governance & Nominations sub-committee – advises all matters of governance including on the composition of the board, board development and recruitment.
- Quality & Safety sub-committee - oversees matters of quality, safety and risk management in our services and across the organisation.

- Remuneration sub-committee - sets the CEO's objectives, appraises the CEO and reports to the Board on the CEO's performance.
- Research sub-committee - This new sub-committee was established in 2023 to provide expert advice to the Board on matters relating to epilepsy research and furthering our strategic objective of funding and collaborating with research partners to increase knowledge of epilepsy, its causes, effects and management.

Organisational Resourcing and Structural Investment

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

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

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

Board Attendance	Feb	Mar	May	July	Sept	Oct	Dec
C Grieve	√	√	√	√	√	X	√
C O'Dea	√	√	√	X	√	√	√
P Kehoe	X	√	√	X	X	√	√
M Fitzsimons	X	√	X	X	√	√	√
A Kealy	√	√	X	√	X	√	√
P Fahey	√	√	√	√	X	√	√
M King	√	√	√	√	X	X	√
A Kilroy	√	√	√	√	√	√	√
H Behan	√	√	X	√	√	√	√
D Gray	X	√	√				
S O'Brien	√	√	√				
M Dowdall	√	√	√				
N Saarsteiner		√	√	X	X	√	√
M Curran		√	√	√	√	√	√
A Chalke							√
N Nagle							√
A Maguire							√

√ Attended X Apologies Not Member

FINANCIAL STATEMENTS

Financial Report

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

This is the first surplus recorded since 2020 and is mainly because of unexpected income from legacies during the year totalling €204,471. However, several other fundraising activities, including funds raised through supporter events and challenges, collections and non-government grants also performed better than in 2022 and ahead of 2023 expectations. Additional one-off HSE funding to address rising costs of providing services and increased income from training services were also important factors in ensuring that income increased by over €338,000 compared to 2022.

Although overall expenditure increased to €1.722m (2022: €1.638m), this too was within budget and is the result of an ongoing close focus on managing costs across our work in programmes, fundraising, administration, compliance, and strategic projects. Staff costs were broadly similar to the previous year and to budget.

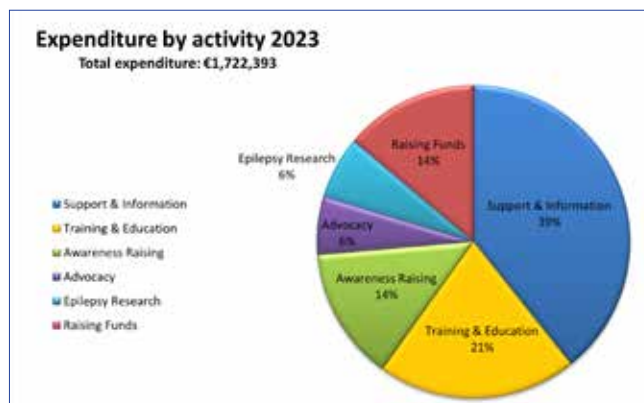
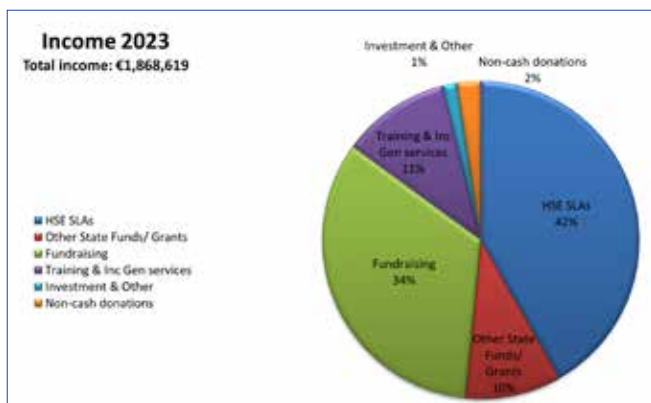
To provide more detailed information on the performance and financial position of the charity, Epilepsy Ireland prepares our financial statements in accordance with the Charities Statement of Recommended Practice (SORP) and FRS102. The full financial statements are available from epilepsy.ie or from info@epilepsy.ie.

A detailed analysis of how we raise and use our funds is also available on our website at: epilepsy.ie/content/use-funds.

Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Statement of Financial Activities (Incorporating Income and Expenditure Account)
for the Financial Year Ended 31 December 2023.

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



Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Balance Sheet
As at 31 December 2023

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



Epilepsy Ireland,
249 Crumlin Road,
Dublin 12. D12 RW92
Tel: 01 455 7500
info@epilepsy.ie
www.epilepsy.ie

Registered Charity Number: 20010553
CHY Number: 6170
Brainwave The Irish Epilepsy Association t/a
Epilepsy Ireland is a Company Limited by Guarantee.
Registered in Dublin,
Company Registration Number 77588

Auditors:
Mazars Chartered Accountants & Statutory Audit Firm
Block 3, Harcourt Centre, Harcourt Road, Dublin 2, D02 A339.



The Scheme to Support National Organisations is funded by the Government of Ireland through the Department of Rural and Community Development.