

# **ANNUAL REPORT 2022**

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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 - 20226 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 2022 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 code 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.





# OUR PEOPLE

(as at 31st December 2022)

#### **Board of Directors**

Ms Cathy Grieve (Chairperson) Ms Clare O'Dea (Secretary) Mr Paul Kehoe (Treasurer) Ms Helen Behan Mr Mark Dowdall Mr Paul Fahey Ms Mary Fitzsimons Mr Derry Gray Mr Ambrose Kealy Dr. Anne Kilroy Prof. Mary King Mr Shane O'Brien

#### Finance & Audit sub-committee

Mr Shane O'Brien (Chairperson) Mr Derek Heffernan Mr Paul Kehoe Mr Tony Rhatigan Ms Cathy Grieve Mr. Owen McCarthy Mr. Allan Barrett

#### **Research Peer Review Board**

Prof. Martin Brodie (Chairman) Ms Ailbhe Benson Prof. Gianpiero Cavalleri Prof. Norman Delanty Dr Patrick Dicker Ms. Cora Flynn ANP Prof. David Henshall Dr Bryan Lynch Dr Cathy Madigan Ms Margaret McCahill

#### **Quality & Safety sub-committee**

Clare O'Dea Anne Kilroy Mary Fitzsimons Peter Murphy Tara Smith

#### **Governance & Nominations sub-committee**

Cathy Grieve Clare O'Dea Ambrose Kealy Helen Behan

#### **Remuneration sub-committee**

Mark Dowdall Derry Gray Cathy Grieve

#### Sustainability & Business Development sub-committee

Paul Kehoe Clare O'Dea Ambrose Kealy Tony Caravousanos Peter Murphy

#### 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) Vacant as of 31/12/22 (Southern Region, Kerry) Vacant as of 31/12/22 (Mid West Region) Catherine Caffrey (West Region) Agnes Mooney (North West Region) Mary Baker (North East Region)

#### **Epilepsy Specialist Nurse**

Sinead Murphy, RANP (Beaumont Hospital)

Training & Quality Manager Edel Curran

Training For Success Manager Maire Tansey Training for Success Administration Assistant Jennifer Jimoh

#### FUNDRAISING, COMMUNICATIONS AND ADMINISTRATION

Advocacy & Communications Manager Paddy McGeoghegan

Fundraising & Development Manager Vacant

Membership & Fundraising Officer Ashley Butler

**Reception & Churchgate Collections** Barbara Doyle

Finance Manager Deirdre Noyes

**Executive Assistant** Catherine Powell

# A MESSAGE FROM OUR CHAIRPERSON AND CEO



Welcome to our Annual Report for 2022, a year in which the organisation revisited, reviewed, and restated its core purpose through the launch of our new Strategic Plan, which will take us through to 2026.

The Plan is the culmination of an intensive process of consultation with members, service users, volunteers, staff,

and representatives from the medical & scientific community. This work began in 2021 during a time of great challenge and tribulation, but also during a period when creativity and problemsolving were in abundance as we all came to terms with adapting to the pandemic environment.

These factors helped to shape our strategy, as well as the commitment and passion for the cause of epilepsy shown by every person who took part in the process.

Our mission has been updated to encapsulate two themes that came up repeatedly in our workshops – empowerment and supporting people to achieve their potential. We also defined our core organisational values for the first time and restated six key strategic aims for the years ahead, e.g. Empowering people with epilepsy through support and education or increasing and diversifying our income. This report is now structured according to these aims. While much of our existing core work remains central in the new plan, new themes such as engagement, collaboration and capacity building are elevated in importance. I am confident that our strategy will effectively guide our activities and prioritise how we invest our limited resources in the coming years. Most importantly, it will shape how we develop as an organisation in order to remain the best possible resource in supporting and representing the 45,000 people living with epilepsy and their families. As you read on, I hope this is reflected in the positive start we made to 2022.

I want to thank everyone who participated in the development of the strategy, as well as everyone who helped make Epilepsy Ireland's year in 2022 one to be proud of. In particular, thank you to our board for their dedication and stewardship of our organisation; our dedicated management and staff team for going above and beyond to progress our journey towards our vision; and most importantly, thank you to our members, supporters and volunteers - without you, our work laid out in this report would not be possible.

Unfortunately, I have to end on a note of sadness. In August, we learned of the death of former Epilepsy Ireland board member and great friend to the organisation, Major General Vincent Savino (Retd.). 'Vinny' had stepped down from the Board earlier in 2022. He was with Epilepsy Ireland for many years, originally prompted by the diagnosis of a close family member. He was instrumental in the charity's fundraising in the 1980s and 90s, and was a source of great wisdom, sound judgement and strategic clarity during his time. He was a wonderful ambassador for epilepsy and we miss him terribly. Ar dheis Dé go raibh a anam.

Cathy Grieve, Chairperson



Thank you for taking the time to read about Epilepsy Ireland's 2022. Thankfully, it was a year in which COVID-19 was not the dominant feature it had been in previous years, although other external challenges such as the cost-of-living crisis did impact on our organisation.

This, however, did not impact on the demand for our services

supporting people with epilepsy and their families. Our report for 2022 will outline the highlights from an incredibly busy year and how we worked towards our six key strategic aims, defined in our new Strategic Plan 2022-2026.

The Strategic Plan was launched at our National Conference in September, following an extensive consultation process with all of Epilepsy Ireland's key stakeholder groups – most importantly, people with epilepsy and their families. The plan is ambitious and will require further resourcing throughout its lifetime, but as you will see from the work outlined in this report, our team are committed to achieving our key goals and working towards our overall vision of a society in which no person's life is limited by epilepsy.

The staff team itself also underwent a lot of change in 2022, with now former colleagues moving onto pastures new, and an influx of new faces joining our team. One such departure was our long-serving Training Manager, Paul Sharkey, who began a well-deserved retirement in April after 24 years with Epilepsy Ireland. Paul's stewardship of our training programme on Epilepsy Awareness and the Administration of Buccal Midazolam was instrumental in developing this important and potentially lifesaving service into the core part of our work it is today, supporting up to 3,000 trainees annually. We wish him health and happiness in his retirement.

As you'll see in the report, some of the year's highlights included hosting over 120 events during the year; responding to almost 20,000 support contacts; launching new services such as mindfulness sessions; providing epilepsy training to over 2,500 health, care and education professionals; funding five new epilepsy research projects and hitting the €1.5m milestone in research investment; running one of our most creative and successful public awareness campaigns for #EpilepsyDay; and making considerable progress on several important advocacy issues. Financially, it was a difficult year, with a not unexpected but significant deficit recorded in order to achieve these results.

I want to pay tribute to all our members, volunteers and supporters for your support during the year. With a more "normal" environment returning in 2022, it was clear that you were eager to get back out there in support of Epilepsy Ireland's fundraising across the year through incredible initiatives and events. Thank you for placing your on going trust in Epilepsy Ireland to deliver the supports and the change needed meet the needs of the epilepsy community.

As mentioned, implementing our new Strategic Plan will require further resources and we will need to depend on your continued support to fully achieve the goals we have set. We hope you will continue to be there in the years ahead as we set about making the ambitions of the plan a reality.

Thank you and I hope you enjoy this look back on 2022.

Peter Murphy, CEO

### 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 general public.

#### Contacts

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).

#### **Registered ANP**

Included in individual contacts are 1,334 one-to-one contacts with the El-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 Coombe, and our Lady of Lourdes Hospital in Drogheda. The RANP also provides specialised epilepsy advice and support to our services team, co-delivers online epilepsy educations sessions, participates in Epilepsy Ireland events, and contributes to the review and updating of our information materials.

#### **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 selfmanage 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).

#### **STEPS**

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 (2021: 23).



*Our Community Resource Officers Agnes, Mary & Cliona teamed up to deliver a joint STEPS session for people with epilepsy within their respective regions in 2022.* 

#### **Support Groups**

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.

#### **Training for Success**

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. Epilepsy Ireland 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. Six students began the 2022/23 programme in September 2022.

#### **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. 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).

#### **Special Events**

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 El CROs and Advanced Nurse Practitioners for people recently diagnosed with epilepsy, a successful model of collaboration between El 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.

#### **New service developments**

Alongside the established services outlined there were a number of new developments launched in 2022. These

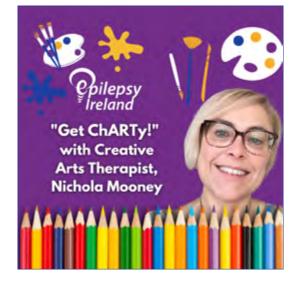


It was fantastic to have the in-person element to our National Conference return in 2022.

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 old's 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.



One of our new service developments in 2023 was the introduction of our 'Get ChARTy' online events for children/young teens with epilepsy.

### **MEMBERSHIP AND ENGAGEMENT**

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

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 via our new Strategic Plan. 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.

#### **Member & Service User Consultation**

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 Community Resource Officers 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 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.

#### Volunteers

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 organising events, participating in El-organised events, campaigns and collections or representing El in marathons, challenges etc. is also vital in continuing our work towards our mission. We are grateful for the support of hundreds of fundraising volunteers each year.

#### **Volunteer of the Year**

Every year, our Volunteer of the Year award acknowledges the outstanding contributions of an individual volunteer or a group of volunteers in support of our organisation. At our 2022 annual conference Louise Young was posthumously recognised as our volunteer of the year. Louise had been an active fundraising and media volunteer for Epilepsy Ireland and since her untimely passing from Sudden Unexpected Death in Epilepsy in 2021, 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 by her family and friends.



Some of the fantastic volunteers behind our National Epilepsy Week campaign in 2022.



Louise's father Stewart, sister Katie and mother Tina receiving Louise's award at our National Conference.

### **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 Manager 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 2022, 2,536 professionals took part in this important training through 236 training sessions (2021: 3,346; 271).

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 2022, 39 individual courses were delivered by our team with 171 parents/carers attending. (2021: 55;194)

#### Collaborating with the HSE and Healthcare Professionals.

Epilepsy Ireland has an important role to play in the development of epilepsy services 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.

In addition to the joint education sessions and our funding of a Registered Advanced Nurse practitioner outlined on Page 5, other collaborations during 2022 aimed at improving the care of people with epilepsy and knowledge of the condition included:

- Collaboration with HSE's Women & Infants Health Programme on a project to identify and meet the information needs of women with epilepsy.
- Working closely with the Irish Epilepsy League on advocacy issues (see page 10) and presenting 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 Anita Kaufmann Foundation to organise Purple Day<sup>®</sup> activities in Ireland.
- Board membership of the Neurological Alliance of Ireland (Director of Services) and the Disability federation of Ireland (CEO).

#### **Investing in Epilepsy Research**

2022 was a landmark year with a record five new epilepsy research 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. In March 2022, our Research Review Committee, 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, UCD; €91,286 investment over three years (50% El, 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 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 a third of the research costs with the IRC funding two thirds.

The three funded applications were as follows:

 miR-CDD: Molecular mechanisms, therapeutic targets and biomarkers for CDKL5 Deficiency Disorder (CDD); €36,000 El 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 El investment over two years, led by Dr Cristina Reschke & Radharani Benvenutti (RCSI). The study aims to identify circadian molecular biomarkers for Dravet pathogenesis and relevant SUDEP-linked phenotypes which may predict SUDEP in this population.
- EPIVIEWS: Exploring Patient Impact & Value in Epilepsy Wearables for Seizure Monitoring; €27,000 El investment over three years, led by Prof Colin Doherty & John David Dalameiro (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. Further details on these, and all projects which Epilepsy Ireland have supported can be found by visiting 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 such as avoiding seizure triggers, avoiding alcohol, and adhering to medication regimens.

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 El will use the data to further increase awareness of epilepsy-related deaths and to emphasise 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 be reaved 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 organised the 'Cycle For Shane' fundraising event in 2022 in memory of Shane Corrigan who died from SUDEP in 2018.



Katie Young addressing the Irish Epilepsy League conference



Cycle for Shane participants embracing at the finish line in Achill after their mammoth cycle from London.

### 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.

#### **International Epilepsy Day**

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.



Our three volunteers in their get-ups for our #EpilepsyDay campaign!

The campaign was released across social media with promoted videos on Facebook, Instagram, YouTube, Snapchat and TikTok – as well as digital advertising on the RTÉ 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, RTÉ Drivetime, several regional media outlets and there was a fantastic piece on News2day featuring a young El 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 Campaigns**

While #EpilepsyDay is our key campaign day of the year, we contribute to and promoted many other awareness raising efforts in 2022, including the following:

• 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 El 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.

- SUDEP Action Day (October): See Page 9
- 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 aimed at both new/ prospective parents and health professionals.

#### Advocacy

Work continued on several key Epilepsy Ireland campaigns in 2022.

• Sodium Valproate

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 valproaterelated 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.

#### Leaving Cert Exams

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 SEC 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.

#### Access to Free Travel

At the beginning 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.

#### **Other advocacy work**

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 NCPE 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 El 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 El volunteer at a Leinster House briefing to elected representatives.

#### **Website and General Communications**

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.

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 El's recent support of Irish research. We continued to actively engage with the media on relevant news items, awareness campaigns and advocacy issues.

### **FUNDRAISING & FUNDING**

Increase and diversify income

#### **Supporter and Volunteer led events**

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 Kirwan 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 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. 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 has been outlined in this report.

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.

#### **State 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 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.

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 HSE and three other Section 39 organisations in one of several full-day facilitated workshops commissioned by the Dialogue Forum in November. 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 SSNO 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.



The East Cork Tribe at the beginning of their epic cycle in Malin.



Friends and family of the late Niall Coughlan after their incredible event in his memory.



Mairéad Power showing off her colours at the top of Kilimanjaro!



Paul and Sean at the end of their epic cycle in Mizen.

### **CAPACITY AND GOVERNANCE**

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

The Epilepsy Ireland 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.

#### **Our Board**

The board is comprised of 12 volunteer members (as of 31 December 2022), drawn from a variety of backgrounds, skillsets, and experiences. Some of the activities of our Board during 2022 are outlined below:

- 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 page 8/9)
- 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).

Board of Directors Meetings	Feb	Mar	April	Мау	July	Sept	0ct	Dec	Total
C Grieve	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$				8/8
C O'Dea	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	Ν				7/8
P Kehoe	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$				$\checkmark$	7/8
H Behan	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$				$\checkmark$	8/8
M Dowdall	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	Ν	$\checkmark$	Ν	6/8
P Fahey		$\checkmark$		$\checkmark$					8/8
M Fitzsimons	$\checkmark$	Ν	$\checkmark$	Ν		$\checkmark$	Ν		5/8
D Gray	$\checkmark$	$\checkmark$	$\checkmark$	(N)	(N)	(N)	(N)	(N)	3/8
A Kealy		Ν	$\checkmark$	Ν	$\checkmark$	Ν			5/8
A Kilroy		$\checkmark$	$\checkmark$	$\checkmark$	Ν	$\checkmark$		$\checkmark$	7/8
M King		Ν	$\checkmark$	$\checkmark$	$\checkmark$	Ν		$\checkmark$	6/8
S O'Brien		$\checkmark$		$\checkmark$					8/8
V Savino	(N)	(N)	(N)	-	-	-	-	-	0/3

√ Present

N Apologies (N) Apologies due to ill health

- No longer a Director

- 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.

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

#### 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 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 subcommittee from January 2022 – Owen McCarthy and Allan Barrett.

#### **Other sub-committees**

Other sub-committees include the Governance & Nominations sub-committee which advises the Board on matters of governance including on the composition of the board, board development and recruitment; the Quality & Safety sub-committee which oversees matters of quality, safety and risk management in our services and across the organisation; the Remuneration sub-committee which sets the CEO's objectives, appraises performance and makes recommendations on management renumeration; and the Business Development & Sustainability sub committee which 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.

#### **Organisational Resourcing and Structural Investment**

Unfortunately, in common with many other Section 39-funded organisations, retention and recruitment of staff was a significant challenge in 2022. 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. Seven successful appointments were made during the year including management posts in finance and in training.

The major focus in 2022 in terms of structural investment 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 at the end of 2022. The system was integrated into our website, and in addition to this, several other functionality and layout improvements were made to the site. A new HR system was also introduced in 2022 to simplify the management and recording of employee records and activities.

### **FINACIAL STATEMENTS**

#### **Financial Report**

In 2022, Epilepsy Ireland reported a deficit of €108,093. (2021: deficit €25,198). Total income was €1.53m, a similar amount to 2021.

While total fundraising was down 7% compared to 2021, when adjusted for a significant one-off legacy donation of €100,000 in 2021, fundraising income showed a 22% increase in 2022 as the impact of the Covid-19 pandemic began to lessen. However, fundraising income remains substantially lower than pre-Covid.

Our total expenditure in 2022 was €1,638,133, an increase of 5% from 2021, mainly as a result of increased activity in research funding and epilepsy awareness. Of every €1 we spent in 2022, 87 cents went to direct charitable objectives, which consists of information & support (41c); training & education (21c); awareness raising (12c); advocacy (6c) and epilepsy research (7c). 13c of every euro was spent on fundraising.

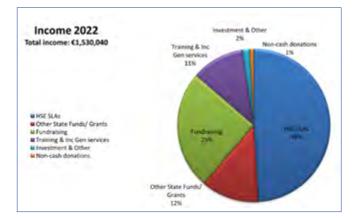
In order to provide more detailed information on the performance and financial position of the charity, Epilepsy Ireland prepares our financial statements in accordance with the Charities Statement of Recommended Practice (SORP) and FRS102. The full financial statements are available from epilepsy.ie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

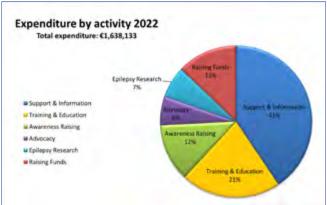
A detailed analysis of how we raise and use our funds is also available on our website at: epilepsy.ie/content/use-funds.

#### 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 2022.

	Restricted Funds 2022	Unrestricted Funds 2022	Total Funds 2022	Restricted Funds 2021	Unrestricted Funds 2021	Total Funds 2021
		€	€	€	€	€
INCOME FROM:	-	-	-			c
Donations and Legacies	23,439	200,509	223,948	51,765	224,362	276,127
Charitable Activities	935,529	174,196	1,109,725	826,193	266,365	1,092,558
Other Trading Activities	32,858	138,892	171,750	34,039	114,841	148,880
Investment Income	-	2,375	2,375	-	2,015	2,015
Other Income	-	22,242	22,242	-	12,800	12,800
Total	991,826	538,214	1,530,040	911,997	620,383	1,532,380
				·		
EXPENDITURE ON:						
Charitable activities	1,065,234	360,954	1,426,188	1,008,844	332,765	1,341,609
Raising funds	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	(98,682)	(9,411)	(108,093)	(130,818)	(105,620)	(25,198)
Taxation	-	-	-	-	-	-
Transfer between funds	80,905	(80,905)	-	34,593	(34,593)	-
Net movement in funds for financial year	(17,777)	(90,316)	(108,093)	(96,225)	71,027	(25,198)
Total funds brought forward	104,182	1,467,409	1,571,591	200,408	1,396,381	1,596,789
Total funds carried forward	86,405	1,377,093	1,463,498	104,182	1,467,409	1,571,591





#### Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Balance Sheet As at 31 December 2022

	2022	2021
	€	€
Fixed Assets		
Tangible assets	139,666	149,021
Current Assets		
Short-term investments	360,000	360,000
Debtors	149,693	129,404
Cash at bank and in hand	1,001,805	1,084,814
	1,511,498	1,574,218
	(187,666) 1,323,832 1,463,498	(151,648) 1,422,570 1,571,591
FUNDS OF THE CHARITY:		
Restricted funds	86,405	104,182
Unrestricted Funds		
- Operational Reserve	942,000	929,387
- Designated funds	435,093	538,022



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

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in Epilepsy Ireland

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



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