



Epilepsy
Ireland

ANNUAL
REPORT
2021

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Front Cover images, Left to right:
Epilepsy Ireland training in action (Pg 8); the Lozanos taking part in Rose Week (Pg 12); the late Brianna Lynch (Pg9); the launch of the National PPI Network in the RCSI (Pg 11); and the late Louise Young (Pg 12).

OUR STRATEGIC AIMS

OUR VISION

Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy.

OUR MISSION

Epilepsy Ireland is committed to working for, and meeting the needs of everyone with epilepsy in Ireland and their families and carers. Our strategic aims are outlined below.

OUR STRATEGIC AIMS

Our Strategic Plan 2017-2021 sets out six strategic aims:

- To provide quality and relevant support, information & advice, meeting the needs of people with epilepsy, their families and carers, professionals and the wider community.
- To communicate effectively with stakeholders; to raise awareness and to improve public understanding of epilepsy; and to advocate for the rights of those with epilepsy, their families and carers.
- To provide relevant training and education services to people with epilepsy, their families, and healthcare and other professionals.
- To undertake, encourage, fund and communicate research into the causes of, cures for and management of epilepsy and into the social and psychological effects of the condition.
- To support people with epilepsy by raising the funds necessary to ensure the short-term funding requirements and long term sustainability of the organisation.
- To operate a stable, progressive organisation meeting all regulatory requirements and striving to implement best-practice standards in the areas of governance, organisational quality, human resources and financial management.

In our Annual Report for 2021, we will set out how we have worked to meet each of these aims throughout the year.

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 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.



Best Practice in Transparency and Accountability

OUR PEOPLE

(as at 31st December 2021)

Board of Directors

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

Finance & Audit sub-committee

Mr Michael Sheehy (Chairman)
Mr Derek Heffernan
Mr Paul Kehoe
Mr Tony Rhatigan
Mr Shane O'Brien
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
Mary Fitzsimons
Peter Murphy
Tara Smith

Governance & Nominations sub-committee

Cathy Grieve
Mark Dowdall
Ambrose Kealy

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
Stephen Lowry

STAFF

Chief Executive

Peter Murphy

SERVICES

Director of Services

Tara Smith

National Information Officer

Geraldine Dunne

Community Resource Officers

Carina Fitzgerald (Eastern Region)
Edel Curran (Eastern Region)
Cliona Molloy (Midlands Region)
Miriam Gray (South East Region)
Sharon O'Connell (Southern Region, Cork)

Niamh Jones (Southern Region, Cork)

Kathryn Foley (Southern Region, Kerry)

Veronica Bon (Mid West Region)
Edel Killarney (West Region)

Agnes Mooney (North West Region)

Mary Baker (North East Region)

Epilepsy Specialist Nurse

Sinead Murphy, rANP (Beaumont Hospital)

Training Manager

Paul Sharkey

Training For Success Manager

Maire Tansey

Training for Success

Administration Assistant

Edel Feely

FUNDRAISING, COMMUNICATIONS AND ADMINISTRATION

Advocacy & Communications Manager

Paddy McGeoghegan

Communications Executive

Jessica Rickard

Head of Fundraising & Development

Stephen Lowry

Membership & Fundraising Officer

Ashley Butler

Reception & Churchgate Collections

Barbara Doyle

Fundraising & Development Executive

Sarah West

Finance Manager

Andrew O'Dwyer

Executive Assistant

Cathy Powell

Welcome to our Annual Report on what has been an incredibly busy 2021.

In a year where so many challenges remained, I am immensely proud of the work of all levels of our organisation to ensure that we continued to be there for people with epilepsy and their families.

I would like to thank everyone who contributed to the work of Epilepsy Ireland throughout the year – our dedicated members, volunteers, and supporters; our staff for their dedication and fortitude throughout these trying times; epilepsy healthcare professionals for their trojan work in difficult circumstances; and finally, my fellow volunteer board members for their tireless work during 2021.

2021 saw the retirement of Tessa Dagge from our board, after over 40 years of voluntary service. Many of the things that our organisation takes for granted now, did not exist when Tessa first got involved in the charity. She has been a genuine pillar of the organisation, including during her time as Chairperson, and she leaves behind an incredible legacy of work. We will miss her presence dearly, but her retirement is fully earned and deserved!

While much of 2021 focussed on protecting services and combatting the challenges arising from the pandemic, it did not stop our organisation from looking ahead to how we can further improve the lives of people living with epilepsy in Ireland.



Last autumn, we embarked on a journey to develop our new strategic plan. At year-end, having organised several consultative workshops with our stakeholders, a clear picture was emerging as to the priorities the organisation needs to address over the coming half-decade. It has been refreshing to look ahead, reassess our vision and hear incredible ideas from our vibrant and dedicated community – ideas which will be reflected in our new strategic plan being announced in September 2022.

Just as we have done in 2021, we will continue to be there for you throughout the duration of this new plan and beyond as we continue our work towards a society where no person's life is limited by epilepsy.

Thank you to all our members, supporters and volunteers who continue to make our work possible.

Cathy Grieve
Chairperson



Thank you for taking the time to read about Epilepsy Ireland's 2021. This was the second year of our organisation adjusting to life with COVID-19 and this is a challenge we have met head on.

With an increased demand for our services and despite the ongoing circumstances, we continued to deliver vital supports to people with epilepsy and their families in living with the condition.

The pandemic continued to pose additional challenges for people with epilepsy and their families and much of EI's work during the year was centred on the impact and consequences of living with Covid - from disseminating disease and vaccine-related information; to supporting people around the medical, psychosocial, quality of life and mental health impacts; our organisation worked to ensure that we were always available for our service users to meet the array of challenges that arose.

Covid-19 also continued to impact our fundraising. Restrictions and social distancing, key weapons in the fight against transmission, impacted the scope of our activities again and the 50% drop in fundraised income experienced in 2020, continued in 2021.

The impact of the pandemic will continue to be felt for many years to come. However, the incredible support of our volunteers, members, and donors in easing the financial impact on

the organisation was inspirational and provides great hope for what we can achieve together when Covid-19 is eventually put behind us.

I want to pay specific tribute to the family and friends of the late Louise Young. Louise was an incredible young woman who was an active volunteer for Epilepsy Ireland. In January 2021, Louise sadly passed away from SUDEP. What happened in the weeks and months following Louise's untimely passing has been incredible with huge fundraising and awareness campaigns organised by Louise's family, friends & colleagues in her honour. The funds raised from these efforts will make an impactful new research project and support service possible in 2022, one that we hope will be a fitting legacy to Louise's memory. Ar dheis Dé go raibh a hanam.

In many ways, our work was 'as normal' in 2021. We organised an innovative and hugely successful awareness campaign in February, achieved notable progress on several advocacy issues and announced a new call for research funding applications. Demand for our training services grew throughout the year, leading to a record number of trainees in the administration of buccal midazolam. Even the National Conference returned – albeit online – after a one-year gap!

Work also began in 2021 on developing a new strategic plan for Epilepsy Ireland to guide our work and direction over the next five years. This plan will be launched in 2022, but for now, I hope that you enjoy our look back at 2021 in this report.

Peter Murphy
CEO

OUR YEAR IN QUOTES

"I'm a parent of an adult child with epilepsy and I still worry about him. He was diagnosed at age 16 having suffered since he was a baby, firstly with febrile convulsions, later with petit mal seizures, and then as a teenager with grand mal seizures - a very frightening and worrying time for our family; thankfully he is now controlled with medication for his seizures. Epilepsy Ireland were there for us when we needed them. We are forever grateful."

*Quote from a service user who accessed our **Support & Information** services.*

"The presentation was excellent, and the facilitator was very warm and open to support everyone."

*Quote from an attendee of our Epilepsy Awareness and Administration of Buccal Midazolam course, one of our key **Training & Education** programmes.*

"While recent efforts have focused on technological solutions it is exciting and very welcome news that anecdotal reports of dogs' ability to predict seizures have now been backed up by scientific evidence."

*Quote from Epilepsy Ireland CEO Peter Murphy, speaking about the Epilepsy Ireland supported **Research** which found untrained dogs can predict seizures.*

"Personally, this analogy is an excellent way of describing what it feels like to experience a seizure. The brain glitches or switches off and needs to reboot. #TimeSafeStay #EpilepsyDay"

*Quote from one of our supporters, commenting on our key **Awareness** campaign on International Epilepsy Day.*

"Well done to all involved in raising awareness of Epilepsy. Wear your Purple proudly tomorrow to support everyone who is affected by epilepsy. Thanks to Epilepsy Ireland for all their wonderful support, advice & kindness. Please Support if you can."

*Quote from one of our supporters in advance of Purple Day®, one of our key **Fundraising** days of the year.*

"Governance is a real strength of Epilepsy Ireland. Examples include: the Division of Responsibilities document is exemplary; the excellent good Code of Conduct; very detailed minutes; the need for and process of gaining good new Board members."

*Quote from our IQ assessment report, one of our key **Governance** achievements in 2021.*

"He raises a good point about epilepsy and I will pursue that with the relevant Ministers. The Deputy is saying that people who are debarred from driving as a result of their condition could have access to free travel. It is outside of the scope of the scheme but it is a fair point."

*Quote from the Taoiseach speaking in the Dáil regarding access to Free Travel for people with epilepsy, one of our key ongoing **Advocacy** campaigns.*

Support and Information

At the core of Epilepsy Ireland’s mission are the support and education services we provide for people with epilepsy and their families. These include one-to-one support, community and hospital-based outreach services; educational programmes, support groups, events & seminars, a range of resources and publications, personal advocacy and individual & group-based self-management programmes.

Our support services are provided by a team of 11 Community Resource Officers (CROs) based in Dublin, Cork, Galway, Shannon, Kilkenny, Killarney, Tullamore, Letterkenny/Sligo and Dundalk. In addition, services are provided by the National Information Officer and through the Epilepsy Ireland-funded Advanced Nurse Practitioner post at Beaumont Hospital.

Our services aim to support people with epilepsy and their families at all stages of their epilepsy journey and 2021 was an extremely busy year for our services team despite the challenges posed by the ongoing COVID-19 pandemic. Remote working continued throughout the year and public health advice meant that opportunities for in-person events, support groups and activities were restricted. However, adaptations introduced in 2020 ensured that the services team continued to provide one-to-one and group-based services in online settings.

Contacts

A total of 22,048 contacts with our service were recorded (2020: 17,384). 11,601 of these were one-to-one contacts (2020: 11,392) by phone, email, Teams/Zoom etc. while 10,477 people attended group-based events and services across the year (2020: 5,992). Group

events included educational/awareness sessions, workshops, our national conference, and self-management & training programmes. Increased public familiarity with technologies such as MS Teams and Zoom meant that there was a marked increase in the number of contacts with our service throughout 2021, with numbers returning to pre-Covid levels. This highlights the value of our services to the community we work with and the importance of continued accessibility during the pandemic.

Service contacts by region 2021

Area	Individual	Group	Total
North-West	495	507	1,002
Mid-West	767	724	1,491
South (Kerry)	783	515	1,298
South (Cork)	1,294	637	1,931
South-East	1,119	949	2,068
Midlands & North East	1,544	2,257	3,801
West	565	415	980
East	3,561	4,042	7,603
Online BM		401	401
RANP	1,473		1,473
TOTAL	11,601	10,447	22,048

While we look forward to returning to more in-person events in 2022, we foresee that online support will continue to be an important aspect of our service due to its popularity and greater accessibility to a wider range of service users.

COVID-19 Response

Our services team continued to support public health efforts throughout the year and provide

specific information concerning COVID-19 and epilepsy to the people we support. Like 2020, concerns related to the impact of COVID-19 were common, including access to medical services, social isolation (and its physical & mental health implications), risks associated with quarantining and parental queries relating to education.

The launch of the national vaccination programme also meant that our service users had numerous initial information needs about specific issues relating to their epilepsy. Our website and social media channels continued to be a particularly important source of information on COVID-related concerns and a video on vaccination we recorded with Professor Norman Delanty was one of the most accessed pages on our website throughout the year.

Events

The move to online delivery of services during the pandemic allowed us to provide special themed events of interest to people with epilepsy and their families throughout 2021. Using our strong relationship with the medical community and the local connections that have been established through our presence in communities across Ireland, we delivered 95 online events in 2021 featuring subject matter experts. These included events for those who were newly diagnosed; women with epilepsy; siblings of children with epilepsy; and parents of children with epilepsy. Other themes included events focused on diet; mental health; medical cannabis in the treatment of epilepsy; and the Ketogenic diet amongst many more. In total, 2,745 people attended these events during 2021.

After a gap in 2020, our National Conference returned for 2021 in online form. The conference consisted of six sessions across three days including sessions for teens on managing their epilepsy; a session on seizure detection devices & alarms; a roundtable discussion on the use of medical cannabis in epilepsy; and an epilepsy research themed session on recent developments. The flexibility provided by the online format ensured a higher attendance than in-person events, with almost 400 people attending over the three days.

As part of Brain Awareness Week 2021, Epilepsy Ireland joined with Migraine Ireland, Acquired Brain Injury Ireland, and MS Ireland to organise a series of seven public events entitled “Building Brain Health while living with a neurological condition”. The events featured leading experts in the fields of mental health, physical therapy and psychology and over 900 people attended the virtual events across the week, highlighting the added value of collaboration and partnership between the wider neurological community in supporting our service users.

Group Supports

Epilepsy Ireland’s support groups provide a safe environment for people with epilepsy and their families to discuss living with the condition in a peer environment. In 2021, 52 online groups were facilitated (2020: 61); with parent-specific groups supported in some regions. In total there were 294 attendees throughout the year (2020: 220).

Other Programmes & Supports

The Living Well with Epilepsy programme is a core element of our service especially for new service users and those with a new diagnosis. Delivered by our CRO team, the main aim of the programme is to help people with epilepsy or parents of children with epilepsy to understand the condition and to provide them with the tools needed to better understand and self-manage epilepsy. In 2021, the programme material was fully updated and redesigned. 234 individuals attended the Living Well with Epilepsy programme in both individual and group settings (2020: 313).

Our STEPS self-management programme for people with epilepsy covers all aspects of epilepsy management and provides broader support and understanding of emotional and mental health, management of stress and positive thinking. In 2021, there were 23 sessions held.

Sláintecare

Work on the Sláintecare Integration Fund project to develop and deliver an education programme for people with a new diagnosis of epilepsy in conjunction with the HSE's epilepsy service was completed. While the initial plan to deliver the project through in-person groups had to be reconsidered due to COVID-19 in early 2020, a re-scoping meant that virtual education sessions continued through 2021. These included large format sessions led by consultant neurologists, while more frequent smaller workshops were facilitated by EI CROs and HSE epilepsy specialist nurses. CROs also provided individual follow up with each attendee as part of the programme.

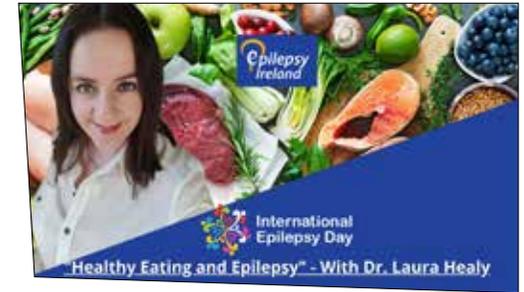
Epilepsy Specialist Nurse

We continued to fund a Registered Advanced Nurse Practitioner (RANP) post at Beaumont hospital, which has a focus on services for women with epilepsy. The RANP provides outreach clinics in Beaumont Hospital, the National Maternity Hospital, the Rotunda and Our Lady of Lourdes hospital in Drogheda. During 2021 a satellite clinic at St James's/ Coombe was also added. The RANP also provides specialised epilepsy advice and support to Epilepsy Ireland CROs and National Information Officer, participates in Epilepsy Ireland workshops, talks and seminars and contributes to our information materials. In 2021, the RANP recorded 1,473 contacts (2020: 761).

Education Information Packs

As part of our community outreach, during the summer of 2021, we sent all schools in the country a copy of our Education Information Pack. The pack is designed specially for Education providers to help them support child living with epilepsy in their school. We also outlined to each school the services we provide and how we can support them in earning more about epilepsy. This proactive approach led to an extremely busy Autumn for our team, in delivering epilepsy awareness training to schools across the country.

In the lead up to #EpilepsyDay 2021, we held a special event with Dr. Laura Healy on healthy eating.



Our National Conference went virtual for the first-time ever in 2021 and featured well-known faces from across the Epilepsy Community!



In March 2021, Prof Colin Doherty, RANP Sinéad Murphy and Epilepsy Ireland CRO, Mary Baker teamed up to deliver a virtual epilepsy education to over 200 attendees!



In 2021, we teamed up again with the team at Sibshop for a special event for siblings of children with epilepsy.



Training in Epilepsy Awareness & the Administration of Buccal Midazolam

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, including teachers and SNAs. Buccal Midazolam is a rescue medication which is administered during a seizure to reduce seizure duration. The medication can prevent hospital admissions and reduce the incidence of potentially dangerous prolonged seizures. 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 was adapted for online delivery in response to COVID-19 during 2020 and online delivery continued in 2021, with a small number of in-person sessions held in accordance with public health guidelines. In 2021, demand returned to pre-pandemic levels with 3,341 healthcare professionals and teachers trained over 271 courses, a significant increase from the 2,057 trainees and 163 courses in 2020.

Buccal Midazolam Training for Parents/Carers

We also provide demonstrations for parents and carers in administering BM. In 2021, 55 individual online information and demonstration sessions on Buccal Midazolam were delivered, with 194 parents/ caregivers attending (2020: 43;144).

Training for Success

There was a welcome return to the classroom for our students participating in the 2021/22 Training for Success (TFS) programme. TFS is a QQI Level 5 course which is run by Epilepsy Ireland in IT Sligo (now Atlantic Technological University Ireland, Sligo) and is funded by Mayo Sligo Leitrim Educational Training Board. The one-year 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. Operating since 1998, TFS is one of the most unique pillars of our service and one which has a proven impact, with 85% of those who 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.

Having been delivered entirely online in 2020, students were back on campus in 2021 and eight students began the 2021/22 term in September. 11 students had begun the previous 2020/21 programme with six completing in August. Four of the graduates went on to further/ 3rd level education with two progressing to employment.

Epilepsy Awareness in the community

While the frontline of our service is supporting people with epilepsy and their families, as a community-based organisation, our work also extends to the wider community and there has been a particular demand in recent years from schools, preschools, and other education settings for epilepsy awareness training. Our programme aims to raise awareness of epilepsy for those with the responsibility

for ensuring a safe education environment. The content can be tailored but typically includes an introduction to epilepsy; a brief classification of seizure activity; and most importantly, steps that should be taken in responding to seizures at school. In 2021, we delivered 160 talks to education providers, with over 3,100 attendees (2020: 129; 2,463). Specific events were also organised in 2021 for general practitioners, nurses, and employers during the year.



Our Community Resource Officer Veronica virtually delivering an Epilepsy Awareness session to a group of Education providers within her region.

One of our key aims at Epilepsy Ireland is to raise awareness of the condition amongst the public in order to help them better understand epilepsy and what they can do to support those living with the condition. Epilepsy Awareness is year round, but we have outlined below some of the key dates within our 2021 year!

International Epilepsy Day

“Time. Safe. Stay!” Three simple words that summarise the key actions to take when responding to a person experiencing a seizure and the key words of our International Epilepsy Day campaign of 2021!

#EpilepsyDay is fronted by Epilepsy Ireland volunteers and in 2021, the leading lights were Nicola O’Sullivan, Grace D’Arcy, Leah Murphy, Wayne O’Reilly, and Oliver Kilmartin. The pandemic presented a great challenge to developing creative content, but this was overcome by our volunteers’ recording content from home which were then worked into videos for social and online distribution. The videos used the analogy of a computer crashing and glitching to explain in plain English what is happening in the brain before, during and after a seizure – while also presenting the key words of what to do to help – Time. Safe. Stay!

Digital advertising was placed on leading websites such as RTÉ and the Irish Times, while print advertising also appeared in the Irish Times. Volunteers across Ireland took to their local airwaves to speak about epilepsy, our campaign and Time, Safe, Stay. There was also significant social media reach with one single post on Facebook reaching over 200,000 people alone while #EpilepsyDay

trended on Twitter across the day. Several politicians supported the campaign, including the Minister for Health who recorded a special message to mark #EpilepsyDay on behalf of the Government. Long-time supporter of Epilepsy Ireland, former Ireland rugby head coach Joe Schmidt also appeared on the Late Late Show to promote the message of Time, Safe, Stay.

The campaign was positively received by the public and our service users for its clear analogy and simple first aid message. It was later shortlisted for an ICAD advertising award, while the previous 2020 campaign was shortlisted for the Inaugural Effie’s award. Though unsuccessful on both occasions, it is positive and encouraging to see our campaigns are being recognised for their impact in changing public perceptions and improving knowledge of epilepsy.

National Epilepsy Week

For National Epilepsy Week in May, we highlighted one key issue each day which is impacting on the lives of people with epilepsy and their families. These included: Sodium Valproate; access to free travel; reasonable accommodations during state exams; Online Media & Safety Regulation Bill and the Medical Cannabis Access Programme. In advance of the week, we highlighted these key issues with TDs and Senators. During the Week, we used our social channels to provide the public with an oversight of each issue and asked our supporters to contact their representatives to raise the issues directly. The campaign helped to advance these issues considerably, in particular the issue of online safety for people with photosensitive epilepsy.

A particular highlight of the week was Senator Denis O’Donovan publicly speaking about his epilepsy diagnosis in the Seanad chamber. This received national headlines and it was an important development for the epilepsy community to see an elected representative speaking about their personal journey with the condition.

SUDEP Action Day

SUDEP Action Day provides a much-needed annual platform to raise awareness of Sudden Unexpected Death in Epilepsy (SUDEP) both publicly and in the epilepsy community. The day also presents an opportunity to remember those who have sadly passed away due to SUDEP. In 2021, we shared two powerful testimonies from families who had lost a loved one due to SUDEP with Arabella Scanlon writing about the loss of her daughter Brianna and journalist Bill Linnane, writing about the loss of his sister Lucy.

We also highlighted the Epilepsy Deaths Register a research collaboration between Epilepsy Ireland and SUDEP Action in the UK. This register allows bereaved families, health professionals and others to provide details of the death of a person with epilepsy. The Register aims to collect and analyse data to better understand the causes and circumstances that surround epilepsy deaths. The Register website was updated fully in 2021 and Epilepsy Ireland contacted all coroners nationwide to encourage them to provide data to the register.

Infantile Spasms Awareness Week

A new development in 2021 saw Epilepsy Ireland joining the Infantile Spasms Awareness Network. This is an international group of organisations dedicated to raising awareness of Infantile Spasms, a type of seizure that occurs in infants which can be extremely subtle and if undetected, can have a serious impact on a child’s development. During the week, we worked with Our Lady’s Children’s Hospital, Crumlin to spread awareness of IS amongst new parents and established a new resource on our website including a video with paediatric neurologist, Dr Mary O’Regan. We look forward to building on this promising start in 2022.



The ad which appeared in the Irish Times - featuring Nicola!

One of our key strategic aims at Epilepsy Ireland is advocating for the needs of people with epilepsy and to reflect the increasing strategic importance of advocacy, the role of Communications Officer was expanded in 2021 to that of Advocacy & Communications Manager. Progress was made in 2021 on several campaigns as outlined below.

Sodium Valproate

We continued to work with our colleagues in OACS Ireland regarding the establishment of an inquiry into the historical licensing and prescribing of Sodium Valproate (Epilim) in Ireland. The HSE estimates that up to 1,250 children have been impacted by the teratogenic effects of the drug since the 1970s and because of this, the Minister of Health announced in November 2020 that an inquiry would be established. Although little progress was made in getting the inquiry established in the first half of the year, productive discussions began with the Department of Health in the latter part of the year regarding the proposed Terms of Reference for the inquiry. We expect that the inquiry will be formally established in 2022.

Alongside the inquiry, we continued to campaign for an improved, coordinated national approach to risk management in pregnancy through the establishment of a Valproate Stakeholder Group, and for the appointment of additional epilepsy nurse specialists to improve HSE capacity to appropriately manage risk communication and management.

Reasonable Accommodations during State Exams

Significant progress was made on this long-standing issue in 2021 when the Minister

for Education announced her intention to provide an alternate sitting of Leaving Certificate Examinations in 2022 for students who are “unable to sit the main set of examinations due to ... categories of serious illness to be determined.” Due to the unpredictable nature of epilepsy and the tendency for seizures to occur at times of high stress, Epilepsy Ireland has campaigned for alternate sittings and other accommodations such as increased continuous assessment and split exams for several years. We welcomed this announcement and although the detail of plans had not been finalised by year end, we continued to work with legislators and the Department to ensure that students with epilepsy are accommodated within the new provisions.

Free Travel & Epilepsy

Epilepsy Ireland has campaigned for many years for access to the Free Travel Scheme for people with epilepsy who are unable to drive due to their epilepsy diagnosis. At present, this is not an automatic entitlement and throughout 2021, we mobilised strong support from elected representatives nationally and encouraged our members to do likewise. We also submitted a pre-budget submission on this issue to the Ministers for Finance, Public Expenditure and Reform, and Social Protection. Towards the end of 2021, the Minister for Social Protection confirmed for the first time that she would meet with Epilepsy Ireland to discuss our proposals in detail. We look forward to pursuing this issue in 2022.

Oireachtas Committee on Media

Epilepsy Ireland appeared before the Oireachtas Committee on Media in 2021 as part of their pre-legislative scrutiny of the

proposed Online Safety & Media Regulation Bill. We highlighted the need for the legislation to protect people with photosensitive epilepsy in Ireland from targeted online attacks using flashing images to deliberately provoke seizures. This has unfortunately become an issue in other jurisdictions and in our presentation, we acknowledged how it was unclear if existing laws were sufficient to deal with such instances.

As a result of our advocacy, we received confirmation from the Attorney General that such attacks could and would be prosecuted under existing criminal law, specifically as assault. This is a welcome clarification that will protect people with photosensitive epilepsy from such attacks becoming commonplace.

Epidyolex Reimbursement

In late 2021, the HSE confirmed that CBD-based medication Epidyolex would be reimbursed in Ireland for use in the treatment of Dravet Syndrome & Lennox-Gastaut Syndrome where certain criteria are met. Epilepsy Ireland had campaigned for the reimbursement of this medication, including via a submission to the National Centre for Pharmacoeconomics in 2020. The approval means that the drug will be available under the medical card, Long-term Illness and Drugs Payment Schemes from 2022.

Other advocacy

Throughout 2021, we continued our work with umbrella organisations both nationally and internationally including the Neurological Alliance of Ireland (NAI); Disability Federation of Ireland (DFI); Health Research Charities Ireland (HRCI); International Bureau for Epilepsy (IBE) and the International League

Against Epilepsy (ILAE). The NAI's Patients Deserve Better campaign was a particularly successful collaborative advocacy campaign, working to address the shortfall of specialist neurology posts in Ireland. We also continued to work with the medical profession on issues including advancing epilepsy e-health and on improving access to the medical cannabis access programme (MCAP) for people with epilepsy.



Minister Humphreys speaking in the Dáil during a debate on access to Free Travel for people with epilepsy.



Advocacy & Communications Manager, Paddy McGeoghegan, addressing the Committee regarding the Online Safety & Media Regulation Bill.

Since 2009, Epilepsy Ireland has operated a Research Funding Scheme, investing in high quality, high-impact Irish epilepsy research. Studies funded have included basic, clinical, psychosocial, genetic and health services research. The scheme aims to support research that has the potential to add significantly to existing knowledge into the causes, cures, care, treatment, impact and effect of any type of epilepsy, including SUDEP. Prior to 2021, over €1.1 million had been invested in 15 projects and in 2021, one new project was funded.

New & Ongoing projects funded

The new study takes place at NUI Galway and is led by James Britton under the supervision of Dr Leo Quinlan (Department of Physiology, School of Medicine). It will investigate an emerging technology called ultrasonic stimulation as a potential non-invasive novel intervention in a group of rare, difficult to treat epilepsies such as Dravet Syndrome & Lennox-Gastaut Syndrome. The work will study whether this technology can regulate electrical activity in the brain associated with seizures, and if successful, may lead to the development of new treatments in the future. Our investment totals €30,656 over two years via the Irish Research Council's Enterprise Partnership Scheme.

Work continued in 2021 on several other projects previously supported by Epilepsy Ireland. Unfortunately, COVID-19 has had an impact on the completion of ongoing medical research and some projects have been delayed and provided with extensions. Ongoing projects include:

- An Analysis of the Current Implementation and Societal Impact of Group 1 and Group 2 Driving Restrictions in both Newly Diagnosed and Established Patients with Epilepsy (RCSI, 2020; €15,000)

- Epilepsy Mortality in Ireland (HRB, 2020: €25,000)
- The microbiome as an environmental trigger for autoimmune epilepsy (RCSI, 2018: €74,500)
- MicroRNAs in the mechanism of ketogenic diet therapies and as biomarkers in paediatric epilepsy (RCSI, 2016: €72,000)

Outcomes of research projects funded

Since 2016, Epilepsy Ireland has supported research at Queens University Belfast investigating whether untrained pet dogs could predict seizures by recognising and reacting to particular odours associated with seizures in humans. In 2021, findings were published by Dr Neil Powell highlighting that all dogs in the study displayed behavioural changes when confronted with seizure-related odours compared to non-seizure control odours. The study received significant media attention and has important practical implications for people with epilepsy – it is hoped that by training dogs to alert their owners of an impending seizure, we can reduce the unpredictable nature of the condition, the injuries associated with seizure-related falls and improve people's quality of life and physical & psychological well-being.

Epilepsy Ireland also previously supported research on the development and role of an epilepsy electronic patient portal (e-Portal) as part of the HSE's Epilepsy Electronic Patient Record (EPR). On completion of the study, findings were published in two papers in the journal *Epilepsy & Behaviour* in 2021. The importance of e-health innovations like the e-portal was brought to the fore during Covid-19 and the work was highlighted as an example of good e-health practice at the Opening Symposium of the 2021 International Epilepsy Congress. Epilepsy Ireland and

medical professional colleagues will continue to work on embedding the e-Portal in the ongoing development of the Epilepsy EPR.

Research Communications

In 2021, we partnered with RCSI/ FutureNeuro on a series of SFI-funded online workshops which brought together researchers, healthcare professionals, people with epilepsy and their families in one forum to discuss key epilepsy research areas. The areas of focus were set in consultation with Epilepsy Ireland service users and were SUDEP, temporal lobe epilepsy, gene therapy and the use of technology in monitoring epilepsy. Each workshop featured a presentation from a leading expert or researcher working on these topics followed by group discussion on the importance of research; how it can be better communicated; and how the research community can help foster in an environment that includes people with epilepsy within their projects. The events also addressed important considerations about finding reliable research online and empowering people to better understand and interpret scientific publications.

Future Research plans

In September 2021, Epilepsy Ireland announced the 8th Research Call since our research funding scheme was established in 2010. Applications were requested for 1–3-year projects to a maximum of €50,000 p.a. Following a consultation with EI service users, the following priorities were set for the call: SUDEP & Epilepsy Mortality; Cannabinoids in Epilepsy; Epilepsy in Women; Psychosocial aspects of epilepsy; and Genetic and molecular mechanisms of epilepsy. A total of six proposals were received and at year end, international peer-review of applications was set to begin. At the end of the assessment

stage, the highest-ranking proposals will be submitted to the Health Research Board in 2022 for co-funding under the HRB-HRCI Joint Funding Scheme. Successful projects will be co-funded by Epilepsy Ireland and the HRB from Autumn 2022.

In addition, Epilepsy Ireland partnered on three applications to the Irish Research Council's Enterprise Partnership Scheme in December 2021. Under this scheme, EI would fund 1/3 of the research costs on successful applications. Outcomes of these applications will be known in the second quarter of 2022.

Other developments

Epilepsy Ireland partnered with FutureNeuro and the Insight Centre for Data Analytics on a successful EU funding application to establish NeuroInsight, a post-doc research programme that will fund 33 fellowships in Ireland from 2022. The programme will fund data science projects on AI, machine and deep learning, data analysis and integration that address challenges arising from epilepsy and other neurological conditions.

Epilepsy Ireland CEO Peter Murphy co-authored two papers in the leading journal *Epilepsia* on the impact of the COVID-19 pandemic on both epilepsy research and epilepsy care. Over 70 EI service users participated in the epilepsy care study which gathered almost 600 respondents from around the world.

Epilepsy Ireland are local partners with two leading research institutions – Dublin City University and RCSI – on the National PPI Ignite network. The network aims to change research culture to better involve patients and the public in research decision-making processes and in the research process itself.

With the continuation of the COVID-19 pandemic, 2021 saw our fundraising continue to be impacted. Not only did the pandemic affect our supporter's ability to come together and have community led events, but it also affected the wider public financially. In 2021, we continued to experience a 50% drop in fundraised income compared to a "normal" year. However, throughout the year we continued to enhance our digital fundraising model to maximise support for our work throughout what was a difficult year for so many. We also continued to have the fantastic support of our members, supporters, and volunteers who despite the circumstances came up with novel challenges to help raise vital funds for our work across Ireland. In total, €416,540 was raised in support of Epilepsy Ireland throughout the year.

Purple Day®

Since first taking part in Purple Day® activities in 2017, this international epilepsy awareness day has quickly become Epilepsy Ireland's flagship fundraising event of the year. Across the globe, the day is used to create awareness about epilepsy and calls for support for epilepsy organisations. Unlike 2020 when the public facing aspect of the day was cancelled at short notice due to the introduction of the first lockdown, this year we had the opportunity to plan for the COVID-19 environment. The main feature of this was an interactive map on which the public could donate and place a pin where they donated from – in an effort to turn Ireland purple for Purple Day®!! Alongside the map, we had other digital events and challenges being undertaken by our supporters. This meant we had a vibrant and varied range of events taking place in support of our work on Purple

Day®! Thank you to everyone who took part in any way!

Rose Week

Despite the growth of Purple Day®, our national fundraising week, Rose Week continues to be an important date in our calendar to raise vital funds for our work. Again, our efforts primarily took place digitally. Using the map, created for Purple Day®, this was amended to allow the public to plant a virtual rose in support of Epilepsy Ireland. In addition to this, we also had services users share their experience of accessing support from Epilepsy Ireland to highlight to the public the importance of the work we do. Sarah Dromey wrote about her experience of epilepsy and how Epilepsy Ireland work to educate the public about the condition; while Lorraine Lozano wrote about the support she received from Epilepsy Ireland's service after the diagnosis of her daughter Teagan. In addition, the Lozano family also held a virtual challenge throughout Rose Week to raise funds - 50 star-jumps together each day to highlight the fact that there are over 50 types of seizures.

Louise Young – Ar dheis Dé go raibh a hanam

For our entire organisation, the year began under a cloud of sadness following the sudden passing of Epilepsy Ireland Media & Fundraising volunteer, Louise Young in January. Louise was just 24 years old, and her passing was later found to be due to a result of Sudden Unexpected Death in Epilepsy. Despite the monumental loss facing Louise's family, friends, and colleagues, in Louise's memory throughout 2021 they continued to undertake fundraising and awareness initiatives in support of Epilepsy Ireland.

Two such examples of this included Louise's employer, Procurement Leaders announcing Epilepsy Ireland as their new charity partner and undertaking fundraising events year-round to raise funds. One such event – Lou's Relay raised £3,517. In addition, a GoFundMe page set up by Louise's friends in her memory raised €35,630. These are just two specific examples of the countless efforts that have been undertaken to support Epilepsy Ireland in Louise's memory. The phenomenal efforts undertaken in memory of this wonderful young woman have led to the funds being ring-fenced and we plan to launch a new, much-needed service in 2022 in Louise's memory.

Thank You!

Throughout the year and despite the circumstances, we have had unparalleled support from our members, supporters, and volunteers through their fantastic initiatives – be it literally scaling mountains, running triathlons or by simply hosting a Facebook fundraiser. There are too many examples of this support to mention individually and while the words "Thank You" do not capture the immense gratitude we have to every individual or family who have raised funds for us, they are the only words available to us. Thank you, from everyone at Epilepsy Ireland.



An action pic of the Lozano's in the midst of their challenge!



The late Louise Young

The Epilepsy Ireland board of directors is responsible for setting and monitoring the strategic direction and strategy and for ensuring that it is effectively and responsibly governed. The Board delegates operational leadership, management and strategic implementation to the CEO who oversees the wider management and staff team and reports to the Board regularly on all services and activities, as well as administrative and financial matters.

In 2021, Epilepsy Ireland retained the Charities Institute Ireland 'Triple Lock' standard of compliance with the Guidelines for Charitable Organisations on Fundraising from the Public; the Charities Regulator Governance Code; and preparing our financial statements in accordance with SORP for charities. Epilepsy Ireland also attained the Improving Quality (IQ) Foundation quality mark in 2021 for the first time. IQ is a standard developed specifically for smaller non-profit organisations, assessing the organisation's governance and management under the indicators of accountability, welcoming, effectiveness and sustainability. Epilepsy Ireland previously held the Trusted Charity standard from 2015–2021.

Board of Directors

Our board is comprised of 13 volunteer members (at 31 December 2021), drawn from a variety of backgrounds, skillsets and experiences. Nine board members have a direct personal connection to epilepsy (i.e., either they or a close family member lives with the condition).

The board is committed to the highest standards of corporate 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.

The board governs the organisation in accordance with its constitution, which specifies that board members may ordinarily serve up to two four-year terms. Four board members stepped down in 2021 (Carol Saarsteiner, Joyce Senior, Tessa Dagge & Tony Caravousanos) and four new board members were elected to the board (Mary King, Helen Behan, Ann Kilroy and Shane O'Brien). The incoming board members bring particular skills and experiences that help meet the needs and gaps identified in the board's annually updated development plan. We would like to thank our former board members for their dedication to the work of Epilepsy Ireland over their years of service.

The board operates in accordance with a range of governance policies and procedures and with reference to strategic and operational plans. The CEO provides detailed updates of progress against the operational plan and budgets at each board meeting.

Seven board meetings were held in 2021. All meetings were held remotely. During the year, the board:

- Closely monitored the organisation's response to the challenges presented by COVID-19 especially in the areas of service provision and the management of income and expenditure.
- Approved an annual plan and budget for the year and monitored progress throughout the year.
- Agreed to undertake a new strategic planning process for 2022-2026; established a strategic planning group and began work on the development of the plan, including stakeholder consultations.
- Completed all work ahead of obtaining the IQ quality standard
- Approved the organisation's full compliance with the Charities Regulator Governance Code.

- Approved the reorganisation of the charity's deposits.
- Completed a board performance review.
- Approved a new Employee handbook and developed a schedule for the review of all internal policies and procedures
- Agreed to launch a new round of the Epilepsy Ireland Research Funding Scheme

Sub-committees

The Finance & Audit Sub-Committee supports and advises the Board in the management and monitoring of the organisation's finances, business activities and strategic direction. In particular, it advises the board on matters relating to budgeting; monitoring of income and expenditure; financial audit; deposits; financial procedures and controls; risk; and the utilisation of reserves.

The Governance & Nominations sub-committee advises the board on matters of corporate governance including board composition, structure and board recruitment. The Quality & Safety sub-committee oversees the development and implementation of a quality and safety programme across Epilepsy Ireland activities. The Remuneration sub-committee has responsibility for setting the CEO's objectives and evaluating CEO performance. The Business Development & Sustainability sub-committee advises the board on income generation and long-term financial sustainability. Membership of these sub-committees is available on epilepsy.ie.

Board of Directors Meetings		Feb 2th	Mar 29th	May 25th	July 5th	Sept 7th	Oct 18th	Dec 8th
Ms. Cathy Grieve	Chairperson	√	√	√	√	√	√	√
Ms. Clare O'Dea	Honorary Secretary	√	√	√	√	x	√	√
Mr. Paul Kehoe	Treasurer	√	√	√	√	√	x	√
Mrs. Tessa Dagge	Director	√	√	x	x	X		
Mr. Derry Gray	Director	√	√	x	x	√	√	√
Ms. Carol Saarsteiner	Director	√	√	√				
Mr. Tony Caravousanos	Director	x	√	x	√	√		
Mr. Mark Dowdall	Director	√	√	√	√	√	√	√
Ms. Mary Fitzimons	Director	√	x	√	√	√	√	√
Mr. Ambrose Kealy	Director	√	√	√	√	x	√	√
Dr. Joyce Senior	Director	x	x	√	x	x		
Mr. Paul Fahey	Director	√	√	√	√	√	√	√
Mr. Vincent Savino	Director	x	x	x	x	x	x	x
Mr. Shane O'Brien	Director					√	√	x
Dr. Mary King	Director					√	√	√
Mrs. Ann Kilroy	Director					√	√	√
Ms. Helen Behan	Director					√	√	√

√ Attendance x Apologies Resigned Not a Director

Mr. Vincent Savino was unable to attend any board meetings in 2021 due to health reasons.

In 2021, Epilepsy Ireland reported a deficit of €25,198. (2020: surplus €138,771).

Income fell from €1.9m in 2020 to €1.5m in 2021 due to the continuing impact of the pandemic on fundraising activities. Income was in line with expectations as 2020 income included Government grants to help aid the impact of the pandemic, that were no longer available in 2021. Income in 2020 also included a large non-cash donation related to our #EpilepsyDay campaign.

Expenditure in 2021 amounted to €1,577,578 and was in line with expectations. Of every €1 we spent in 2021, 86 cents went to direct charitable objectives, which consists of information & support (43c); training & education (21c); awareness raising (10c); advocacy (8c) and epilepsy research (4c). 14c 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.

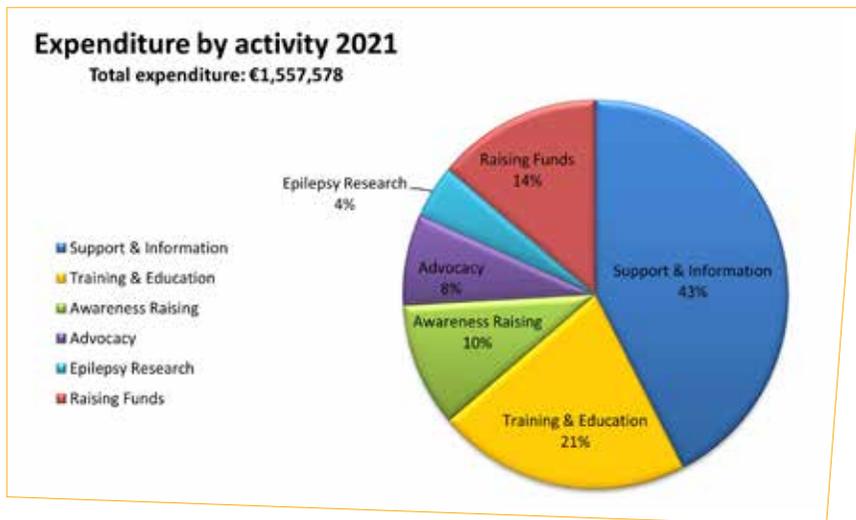
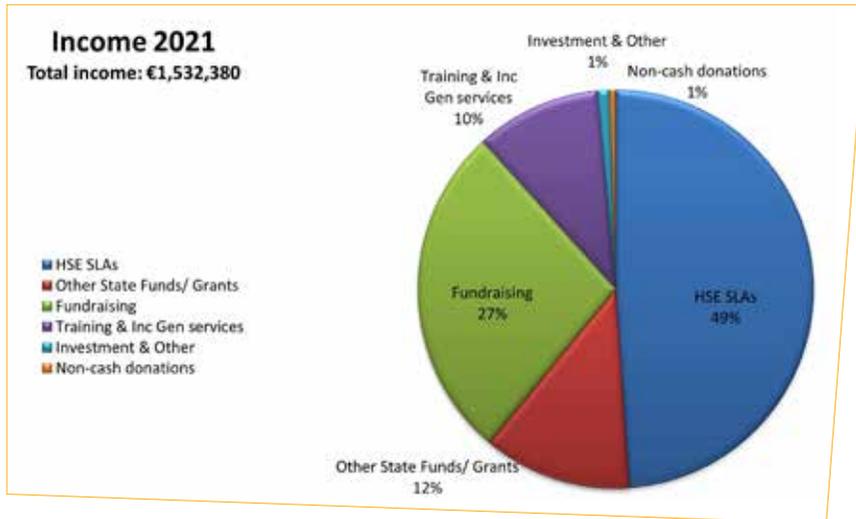
Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Statement of Financial Activities (Incorporating Income and Expenditure Account) for the Financial Year Ended 31 December 2021.

	Restricted Funds 2021 €	Unrestricted Funds 2021 €	Total Funds 2021 €	Restricted Funds 2020 €	Unrestricted Funds 2020 €	Total Funds 2020 €
INCOME FROM:						
Donations and Legacies	51,766	224,361	276,127	252,545	190,628	443,173
Charitable Activities	826,193	266,365	1,092,558	1,161,238	218,667	1,379,905
Other Trading Activities	34,038	114,842	148,880	27,342	75,864	103,206
Investment Income	-	2,015	2,015	-	3,453	3,453
Other Income	-	12,800	12,800	-	31,386	31,386
Total	911,997	620,383	1,532,380	1,441,125	519,998	1,961,123
EXPENDITURE ON:						
Charitable activities	1,008,844	332,765	1,341,609	1,290,529	308,155	1,598,684
Raising funds	33,971	181,998	215,969	86,270	137,398	223,668
Total	1,042,815	514,763	1,557,578	1,376,799	445,553	1,822,352
Net Income/(expenditure) before taxation						
	(130,818)	105,620	(25,198)	64,326	74,445	138,771
Taxation	-	-	-	-	-	-
Net Income/(expenditure)	(130,818)	105,620	(25,198)	64,326	74,445	138,771
Transfer between funds	34,592	(34,592)	-	68,918	(68,918)	-
Net movement in funds	(96,226)	71,028	(25,198)	133,244	5,527	138,771
Total funds brought forward	200,408	1,396,381	1,596,789	67,164	1,390,854	1,458,018
Total funds carried forward	104,182	1,467,409	1,571,591	200,408	1,396,381	1,596,789

Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Balance Sheet as at 31st December 2021.



	2021	2020
	€	€
Fixed Assets		
Tangible assets	<u>149,021</u>	<u>143,467</u>
Current Assets		
Stock	-	-
Debtors	129,404	191,416
Cash at bank and in hand	<u>1,444,814</u>	<u>1,443,251</u>
	1,574,218	1,634,667
Current Liabilities		
Creditors: Amounts falling due within one year	<u>(151,648)</u>	<u>(181,345)</u>
Net Current Assets	<u>1,422,570</u>	<u>1,453,323</u>
TOTAL NET ASSETS	<u><u>1,571,591</u></u>	<u><u>1,596,789</u></u>
FUNDS OF THE CHARITY:		
Restricted funds	104,182	200,408
Unrestricted Funds		
- General funds	929,387	858,359
- Designated funds	538,022	538,022
TOTAL FUNDS	<u><u>1,571,591</u></u>	<u><u>1,596,789</u></u>



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 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:

Deloitte Chartered Accountants

Deloitte & Touche House, Earlsfort Terrace, Dublin 2.



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



Best Practice in Transparency and Accountability

