



ANNUAL
REPORT
2019

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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 as follows:

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 2019, 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 Governance Code for the Community, Voluntary and Charitable Sector in Ireland. As a charity seeking donations from the public, we aim to comply with the Guidelines for Charitable Organisations on Fundraising from the Public.

OUR PEOPLE *(as at 31 December 2019)*

Board of Directors

Ms Cathy Grieve (Chairperson)
Ms Clare O'Dea (Secretary)
Mr Paul Kehoe (Treasurer)
Mr Tony Caravousanos
Mrs Tessa Dagge
Mr Mark Dowdall
Ms Mary Fitzsimons
Mr Derry Gray
Mr Ambrose Kealy
Ms Carol Saarsteiner
Mr Vincent Savino
Dr Joyce Senior

Finance & Audit sub-committee

Mr Michael Sheehy (Chairman)
Mrs Tessa Dagge
Mr Mark Dowdall
Ms Cathy Grieve
Mr Derek Heffernan
Mr Paul Kehoe
Mr Shane O'Brien
Mr Tony Rhatigan

Quality & Safety sub-committee

Ms Mary Fitzsimons
Ms Clare O'Dea
Mr Peter Murphy
Ms Tara Smith

Governance & Nominations sub-committee

Mr Mark Dowdall
Ms Cathy Grieve
Mr Ambrose Kealy

Remuneration sub-committee

Mr Mark Dowdall
Mr Derry Gray
Ms Cathy Grieve

Business Development & Sustainability sub-committee

Mr Paul Kehoe (Chairman)
Mr. Tony Caravousanos
Mr. Ambrose Kealy
Ms. Clare O'Dea
Ms. Carol Saarsteiner

Research Peer Review Board

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

STAFF

Chief Executive

Peter Murphy

Services & Training

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)
Loretta Kennedy (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)

Fundraising, Communications and Administration

Fundraising & Communications Manager

Michael Carty

Communications Officer

Paddy McGeoghegan

Membership & Fundraising Officer

Ashley Butler

Churchgate Collections Administrator

Barbara Doyle

Fundraising Assistants

Luke Meany
Judith Kelleher

Training Manager

Paul Sharkey

Training For Success Manager

Maire Tansey

Training For Success Facilitator

Edel Feely

Finance Manager

Andrew O'Dwyer

Executive Assistant

Cathy Powell

Receptionists

Madge Geoghegan
Joan McDermott

Community Employment Scheme

Ruth Healy

A MESSAGE FROM OUR CHAIRPERSON, CATHY GRIEVE



It is a great privilege to present our annual report for 2019 – my first time doing so as Chairperson of Epilepsy Ireland. I was honoured to be elected to the role in December 2019, becoming the first person with epilepsy to serve as Chair in the history of the organisation. My motivation in this role will be to ensure that Epilepsy

Ireland continues to deliver on our vision of a society where no person's life is limited by epilepsy.

I would like to pay tribute to my predecessor, Mark Dowdall and thank him for his outstanding work since 2013. Mark's commitment to ensuring the Board operated to the highest standards of governance and his focus on promoting quality, across all the organisation's work, has put the organisation on a strong footing to meet the challenges ahead.

As we navigate through the most uncertain of times, I am confident that the processes and people in place are fully equipped to guide the organisation forward. I know that all our stakeholders can be equally reassured about the quality of our work, how the organisation is run and how funds raised are put to good use supporting and representing people with epilepsy.

I also want to thank our directors who stood down from the

Board in 2019 – Michael McLoughlin, Prof Norman Delanty, Dr Michael Hennessey, Dr Brian McNamara, Dr Bryan Lynch and Dr Brian Sweeney for their contributions to Epilepsy Ireland over many years and in the case of the clinicians, their ongoing clinical work in relieving the huge burden of epilepsy in Ireland. They will continue to play an important part in supporting our goals.

Looking at 2019, the vital role and impact of Epilepsy Ireland is evident. We are proud of our achievements and regardless of the new challenges posed by Covid-19, we remain focused on our mission to meet the needs of all those affected by epilepsy in Ireland.

Our ability to make a difference relies on ensuring that we can raise the funds needed for our services, training, awareness-raising, advocacy and research. We are already fortunate to have some of the most dedicated members, volunteers & supporters who help us raise vital funds every year.

Without you, none of what we do at EI would be possible. Thank you for your support in 2019 and please do continue to champion our work – the impact of the global pandemic means that we need you now more than ever.

At this time, you or a loved one may need Epilepsy Ireland - know that we are here, ready to support anyone with epilepsy, their families and carers.

A MESSAGE FROM OUR CEO, PETER MURPHY



Thank you for taking the time to read about Epilepsy Ireland's activities throughout 2019.

We once again witnessed an increase in demand for our support and training services. Our ability to meet this demand is testament to the fantastic work which is being done by our dedicated service and training team

who are the front-line of our work at Epilepsy Ireland, as well as all the team that back them up.

We responded to 12% more contacts in 2019 compared to the previous year, most of which was a result of increased one-to-one support work. We also worked with more new service users than ever before while another key development was a renewed focus on partnering with HSE epilepsy services to jointly deliver programmes for people with epilepsy and their families.

Our training programme for health and allied health professionals experienced a 33% increase in 2019, while our flagship Training For Success course celebrated its 21st birthday, marked also by the retirement of long-serving course manager Honor Broderick who guided over 250 students through the programme on to further education or employment. Thank you Honor!

There were many other notable successes across the areas of advocacy, awareness-raising and research which you can

read more about within, from the growing popularity of Purple Day to celebrating the milestone €1m invested in epilepsy research across the decade.

Financially, we had a solid year in 2019 with income covering expenditure, due in part to new grant funding which helped reduce HSE funding deficits and due, as ever, to the thousands of generous people who contribute their time and money to support our work.

While our annual report focuses on 2019, it is impossible to ignore the new challenges that 2020 has brought about. Just eight short months ago, as we signed off our plans for the year, we never could have foreseen the impact that Covid-19 would have on our work and on our fundraising. Our original goals for the year have been replaced by new challenges. Most importantly, we will need to adapt how we deliver our services safely to those who rely on us, and equally critical is the need to ensure that we raise the funds needed to do so, from all available sources. These are challenges that we are tackling head-on. However, we expect our fundraising to decline by 50% this year which is likely to affect our ability to invest across all our activities in 2021 and beyond.

As the only national organisation for people with epilepsy and their families, I want to appeal to all our generous supporters and to everyone with an interest in the condition of epilepsy to please donate or get involved in our fundraising in 2020 and help us continue to make the impact we have delivered since 1966. Thank you in advance for your support.

OUR YEAR IN NUMBERS

With **40,000** people living with Epilepsy in Ireland today and our service co-ordinated by our **9** regional offices and

11 Community Resource Officers,

our year in numbers is as follows:

2,774 new services user compared to **2,449** in 2018

21,821 individual contacts with services users in 2019,

up from **19,447** in 2018...

we held **61** local support group events...

...**277** training sessions with professionals on Buccal Midazolam delivered,

up from **199** in 2018...

... and **2,871** trainees, up from **2,146** in 2018...

4,659 teachers, SNAs and students attended

156 training days nationwide

... and

2,745 people attended our community epilepsy awareness sessions...

...we continued to support Irish epilepsy research throughout 2019,

passing **€1,000,000** now invested since 2010...

...over **30** buildings lit up Purple on March 26th

in support of epilepsy awareness...

... **1** National Conference with over **200** attendees...

... **10** students participated in Training For Success...

...We connected with **16,000** Facebook followers

and **4,400** twitter followers...

... and thanks to our members, volunteers and donors,

€594,762 was raised

to support our work during the year.

THANK YOU!

SUPPORT & INFORMATION

Support Service Overview

Epilepsy Ireland provides a range of support services for people living with epilepsy and family members including one-to-one support, educational programmes, support groups, individual and group-based self-management programmes, community and hospital-based outreach services and a nurse-led helpline. Our staff team also develop and coordinate local seminars, family days, workshops and events in addition to producing a range of resources and publications.

These services are provided from our head office in Dublin and from regional offices in Cork, Galway, Limerick, Kilkenny, Dundalk, Killarney, Letterkenny and Tullamore. Our Services team is comprised of 11 part-time Community Resource Officers (CROs), Information Officer and Epilepsy Ireland funded Epilepsy Nurse Specialists, all of whom are overseen by the Director of Services.

Services analysis 2019

As has been the trend in recent years (see Fig 1), demand for our services increased in 2019. We recorded an increase in individual contacts with services users from 19,447 in 2018 to 21,821 in 2019. We also worked with an increased number of new service users in 2019 (2,774 compared to 2,449 in 2018).

Fig.1 Total Service contacts with Epilepsy Ireland 2014-2019



Service contacts by region 2019

	Individual	Group	Total
North-West	465	1,001	1,466
Mid-West	565	922	1,487
South (Kerry)	744	750	1,494
South (Cork)	897	1,996	2,893
South-East	896	915	1,811
Midlands + North East	726	1,320	2,046
West	389	474	863
East	5,156	4,606	9,762
Total	9,837	11,984	21,821

One-to-One Supports

One-to-one contacts with our CROs, Information Officer, Training Manager and Epilepsy Nurses totalled 11,984 in 2019 (2018: 9,794).

An important core service is the Living Well with Epilepsy 'Toolkit' Programme. This programme is aimed at individuals/parents of children with a new diagnosis of epilepsy. In 2019, 300 people completed the programme. Since it was developed in 2014, we have now delivered the programme with almost 2,300 individual service-users.

Group-based supports

Contacts with individuals in group settings including educational/ awareness sessions, group self-management and training programmes totalled 9,836 in 2019 (2018: 9,653). Regional support groups are facilitated by CROs across the country, providing an informal opportunity to share information, offer and receive mutual support. In 2019 there were 61 support group events (2018: 51) with 493 (2018: 553) people attending.

Our CRO team also facilitate group-based self-management programmes for adults and parents. These group-based programmes include Support and Training in Epilepsy Self-management (STEPS) and Parents STEPS. These programmes enable people to learn more about epilepsy and the tools and knowledge to become experts in managing their own epilepsy. We also provide an advanced self-management programme called Innerwise, which focuses on improving mental health and wellbeing, managing stress and developing life management skills through tools such as mindfulness and meditation. A total of 9 self-management programmes were organised in 2019 (2018: 20).

Working with HSE services

Reduced demand for some group-based programmes highlights a growing need for more personalised and one-to-one supports, in part as a result of increasing complexity in individual support cases. It is also a function of a strategic shift in focus to working more in partnership with HSE hospital services in recent years and incoming referrals from Epilepsy Specialist Nurses (ESNs), Neurologists and Paediatric Neurology teams.

We also maintain an active hospital outreach service. Education sessions delivered jointly by CROs and HSE ESNs continue to be an important service delivered on-site at epilepsy clinics. There were 70 sessions held in hospital settings in 2019 (2018: 68) with 412 (2018: 413) patients availing of this support.

Data from the Epilepsy Partnership in Care (EPIC) study on patient centred care in epilepsy was published in 2019. The study, led by RCSI and NUI Maynooth highlighted the importance of developing deeper collaboration between Epilepsy Ireland CROs and hospital-based epilepsy specialist nurses, and the benefits that would accrue for patients with epilepsy. Active participation in this research has helped develop stronger links and collaborative efforts between Epilepsy Ireland and HSE epilepsy services in recent years.

This study was also the inspiration for a new Slaintecare-funded pilot project beginning in late 2019 to further develop collaboration with hospital services and jointly deliver an education programme to patients with a new diagnosis of epilepsy.

Epilepsy Specialist Nurses

Epilepsy Ireland has a long history of supporting epilepsy nursing posts in the health service and in 2019, the funded candidate Advanced Nurse Practitioner (cANP) post at Beaumont hospital became a registered ANP (RANP), with 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. The RANP also provides specialised epilepsy advice and support to Epilepsy Ireland CROs and National Information Officer, participates in workshops, talks and seminars and contributes to Epilepsy Ireland publications.

We also continued to fund the Epilepsy Transition Coordinator post with the Children's Hospital Group to the completion of the three-year project in May 2019. Epilepsy Ireland's support over three years led to the setting up of dedicated transition services in Beaumont and St. James's hospitals, the establishment of a transition registry and the development of transition pathways from children to adult services.

Events

The 2019 National Epilepsy Conference took place in Cork in September with over 200 people attending to learn about the latest developments in epilepsy care, research and services and to take part in epilepsy workshops.

Following on from successful events in 2018, two 'Heads-Up' conferences were held in March in Limerick and Meath. These events focused on issues around memory, cognition and mental wellbeing for adults with epilepsy and were originally developed in response to feedback from our service users.

Other notable events included three workshops on issues arising for women with epilepsy, held in Galway, Kilkenny and Cork. We also assisted with an international Policing seminar held in Dublin, highlighting epilepsy awareness and responding to seizures to a key target audience.

Information & Education Resources

We continually review and update our epilepsy information materials and in 2019, revised resources published by Epilepsy Ireland included 'Epilepsy Explained, Frequently Asked Questions', 'Safety and Seizures' and 'Epilepsy and Children, A Guide for Parents'. We also worked to distribute our epilepsy guide for teachers and educators, launched in late 2018.

Membership

Epilepsy Ireland is a membership-based organisation and in 2019, we put in place a new membership strategy to recruit new members and retain existing members. This followed a restructuring of our membership packages in 2018, and included incentives such as a new range of discounts and incentives for members. Members continue to receive safety pillows and/or epilepsy wristbands upon joining.

Working with families & younger people

Our annual family fun day took place in July at Dublin Zoo with over 200 attendees from all across the country. The day allowed families to mix with others in a similar situation in a relaxing & fun environment. Regional family events also took place in Kerry and Limerick during the year.

We also aim to work with and support teens and young adults with epilepsy. In 2019, a short media and radio skills programme was piloted with Near FM in Dublin. In addition, two art-based workshops were organised for siblings of young people with epilepsy. The groups were facilitated by SibShops in Dublin and Meath.

Neil Powell of Queen's University Belfast speaking at our National Conference about his research on untrained pet dogs predicting seizures.



Our patron Rick O'Shea encouraging people to become a member of Epilepsy Ireland!



Our team at the annual Family Fun Day taking a break from registrations for a quick snap.



TRAINING & EDUCATION

Buccal Midazolam Training for Professionals.

Since 2009, Epilepsy Ireland has been providing a training programme in Epilepsy Awareness & the Administration of Buccal Midazolam (BM) for health professionals and allied health professionals. The aim of the training programme is for participants to develop a greater understanding of epilepsy in general, understand the role of the emergency rescue medication and receive instruction in the correct administration of BM. The training is delivered by our Training Manager and by our team of Community Resource Officers.

We witnessed continued growth in the demand and delivery of the training during the year. 277 one-day training sessions were delivered in 2019, compared to 199 the previous year. There was also significant growth in the number of trainees which increased from 2,146 in 2018 to 2,871 in 2019, an increase of 33%. EI has many long-standing clients who regularly access the training while new client organisations include a large number of those involved in home care delivery. Almost 12,000 trainees have been trained under the programme since 2009.

In 2019, 94% strongly-agreed or agreed that the programme has improved their ability to deal with the emergency response involving the administration of BM for prolonged/serial seizures.

Buccal Midazolam Training for Parents & Carers

We also provide demonstrations for parents and carers in administering BM. In 2019, 231 parents and carers attended demonstrations, almost double the number of attendees in 2018.

Training for Success

Training for Success (TFS) is Epilepsy Ireland's one-year full-time QQI Level 5 training programme first established in 1998. Based at the Institute of Technology Sligo and funded by the Mayo Sligo Leitrim Education & Training Board, the course makes education more easily accessible to people with epilepsy who, due to their condition have experienced difficulties in the progression of their educational and career aspirations. TFS modules include Epilepsy Management, Research and Study Skills, Word Processing, Mathematics, Communications, Teamwork, Health and Safety at Work, Customer service & Work Experience.

The variety of employment, training and education options in recent years has brought challenges for course recruitment and seven students began the 2018/19 programme, of whom five graduated in 2019. During 2019, we continued to work with TFS partners on recruitment and sustainability measures and 10 students from around the country were welcomed to TFS for the 2019/2020 programme.

Schools Education

2019 was another typically busy year for the Schools Education Programme. This programme aims to raise awareness of epilepsy for those with the responsibility for ensuring a safe education environment. The programme typically includes an introduction to epilepsy; a brief classification of seizure activity; and most importantly, steps that should be taken and avoided in responding to seizures at school. In 2019, 4,659 teachers, SNAs and students attended 156 training days nationwide. 21 off-site Epilepsy Awareness presentations for teachers and SNAs were also organised by Epilepsy Ireland in 2019, with a further 640 professionals attending these evening programmes.

Awareness in the workplace

We also continued to provide epilepsy awareness presentations to various groups that include employers, training organisations and community groups. There was a significant increase in this activity in 2019, with a total of 114 presentations delivered, attended by 2,745 people.

2,871
PROFESSIONALS
WERE TRAINED
IN THE
ADMINISTRATION
OF BUCCAL
MIDAZOLAM
IN 2019



*Our 2018/19
Training
For Success
Graduates.*

EPILEPSY AWARENESS

International Epilepsy Day

International Epilepsy Day is celebrated annually on the second Monday of February to help promote better public understanding of the condition globally. In 2019, Epilepsy Ireland used the day to focus on seizure awareness with Ireland Rugby Head Coach, Joe Schmidt supporting the TEAM campaign:

T – Take care to protect the person

E – Ensure you stay with them

A – Allow the seizure to run its course

M – Move the person onto their side when the seizure is over

The message was promoted online and in the media, supported with a small radio advertising campaign. Joe Schmidt has been an active and high-profile ambassador for epilepsy in recent years, and one of his final engagements as Ireland Head Coach was the annual fundraising lunch in May alongside Kathryn Thomas, BJ Botha, El Patron Rick O'Shea and El member, Eva Ní Shúilleabháin.

Former South Africa rugby international and Munster & Ulster legend BJ Botha also got involved in #EpilepsyDay, talking about his family's experience of living with epilepsy in the media. There was widespread local and national media coverage of the day as well as a strong social media interest where #EpilepsyDay trended at number one in Ireland and reached >100,000 people on Facebook.

Purple Day

Purple Day takes place on March 26th annually and is a key awareness and fundraising event for Epilepsy Ireland. In 2019, there were dozens of coffee mornings held by supporters around the country, Purple Day wristbands were available for purchase in 50 different locations, while a host of schools and companies were involved in fundraising activities using the colour purple. Epilepsy Ireland Patron Rick O'Shea and consultant neurologist Dr. Peter Widdess-Walsh appeared on Ireland AM to discuss epilepsy. Almost 40 well known buildings and landmarks across Ireland also lit up purple that evening to mark the occasion. These included Dublin City Hall, Eyre Square, the National Convention Centre and Kilkenny Castle.

Brain Awareness Week

Brain Awareness Week in March was co-ordinated by the Neurological Alliance of Ireland (NAI) and all Epilepsy Ireland regional offices organised events during the week. The Love Your Brain campaign aimed to promote greater awareness and understanding of the brain and brain conditions as well as the need for more investment in services, research and disease prevention. Love your Brain was supported by over 20 patient organisations including Epilepsy Ireland.

Other awareness events

National Epilepsy Week in May focused on local events including events for teachers, community engagement events and public information stands. International SUDEP Day was held in October and Epilepsy Ireland participated by reaching out to members, service users and the public to inform about SUDEP and also on the critical issue of

managing epilepsy risks. Other activities of note during the year included partnering with Cork Airport in epilepsy awareness training for staff as part of their strategy to assist passengers with hidden disabilities and working more closely with An Garda Síochána to highlight epilepsy awareness.

Online and social media

Our epilepsy.ie website remains a key source of accurate, trusted and up-to-date information and news for all our stakeholders and the general public. Our social media channels (Facebook, Twitter, Instagram and YouTube) are also vital to our work in communicating our activities and news to followers and in raising epilepsy awareness in the public. In 2019, Facebook followers increased from 14,000 to almost 16,000 enabling us to reach a total of over 1.9m people during the year. Our Twitter following grew by 10% to 4,400 while on Instagram, we grew by 25% to over 2,000 followers.

Seizure first aid poster used for International Epilepsy Day 2019.



Our patron Rick O'Shea and Dr. Peter Widdess-Walsh appearing on Ireland AM to discuss Purple Day 2019.



Total Health Pharmacies supported Purple Day epilepsy awareness in 2019.



ADVOCACY

Sodium Valproate Campaign

Following a successful and sustained effort in 2018, work continued on the sodium valproate/ foetal anti-convulsant syndrome (FACS) campaign alongside OACS (Organisation for Anti-Convulsant Syndrome) Ireland focusing on three main issues: reducing the risks of FACS in children being born today; seeking services for families previously affected by in-utero valproate exposure; and establishing an independent investigation into the historical use of valproate in Ireland.

We continued to work for the implementation of the Oireachtas Health Committee's 12 recommendations published in 2018 which address all of these objectives. Following the completion of the HSE's Valproate Response Project in 2019, we were due to revisit the Committee in early 2020 to highlight the need for action on outstanding issues such as vacant nursing posts, access to diagnostics, family support packages and the ever-present need to focus on risk-minimisation measures.

A highlight of the advocacy campaign in 2019 was the "National Conference on the Consequences of Sodium Valproate (Epilim): 50 years on", held in Trinity College in March. The event was jointly organised by the HSE, Epilepsy Ireland and OACS Ireland and attended by patients & families affected by valproate, healthcare professionals and policy makers. It featured presentations from a range of experts from the UK and Ireland in addition to the experiences of families affected and updates on the Irish response to the valproate problem to date. Work continues on this campaign into 2020.



Pictured at the National Conference on the Consequences of Sodium Valproate - Dr Peter Turnpenny, Clinical Geneticist; Geoff Day, OACS Ireland; Karen Keely, OACS Ireland; Peter Murphy, Epilepsy Ireland; Jo Cozens, OACS UK and Dr Jeff Aronson, Clinical Pharmacologist.



Families affected by sodium valproate at the National Conference on the Consequences of Sodium Valproate.

Other Advocacy Issues

Other advocacy-related issues during the year included:

The long-running campaign for access to free travel for people with epilepsy who are prohibited from driving received a boost when the Oireachtas Health Committee supported the campaign in July. The Board also approved funding for a small study on the impact of driving cessation to be undertaken at Beaumont Hospital.

Through an internal working group, work began on the development of an epilepsy advocacy 'manifesto' for Ireland. We consulted with members on the key epilepsy advocacy issues affecting them and at year end, we were in the process of organising focus groups to consult further as well as reaching out to the medical community.

Access to medications was also a common theme during the year; including the impact of Brexit; the Government's steps to introduce the Medical Cannabis Access Programme; and the re-emerging issue of generic substitution/ interchangeability. We also signed the IPPOSI Patient Charter, a call to review patient involvement in the processes of assessing and reimbursing new medicines.

We also continued to work closely with medical professionals through the HSE's National Epilepsy Clinical Care Programme, the Epilepsy Electronic Patient Record steering group, the Irish Epilepsy League and the Irish Epilepsy Nurses Group.

Effective advocacy is also carried out through membership and engagement with representative groups such as the Disability Federation of Ireland (DFI), the Neurological Alliance of Ireland (NAI), The Wheel, Charities Institute Ireland (CII), Health Research Charities Ireland (HRCI) and the International Bureau for Epilepsy (IBE).

Following the publication in 2019 of the Report of the Independent Review Group established by the Minister for Health to examine the relationship between the voluntary sector and the state, Epilepsy Ireland accepted an invitation to address the Oireachtas Health Committee on the issue of Section 39 funding for voluntary organisations. Alongside The Wheel and DFI, we highlighted the role of community-based organisations like Epilepsy Ireland and called for the urgent implementation of the Report's recommendations to address issues around the adequacy of Section 39 funding and a range of other measures.

CEO Peter Murphy and Community Resource Officer for Cork, Niamh Jones pictured after speaking to the Oireachtas Health Committee about our work



RESEARCH

Investing in Research

Epilepsy Ireland operates a Research Funding Scheme to provide epilepsy researchers in Ireland with an avenue to access funding for quality, high-impact research. The scheme has supported a wide range of relevant research questions over the past decade including epilepsy genetics, molecular mechanisms of epilepsy, sudden unexpected death in epilepsy, stigma, family communications, epilepsy specialist nurses, biomarkers, seizure dogs and e-health in epilepsy.

In 2019, we marked the achievement of having invested €1m in research in the decade. We recorded a video featuring funded researchers and people with epilepsy discussing the impact funding has made and we hosted an "Epilepsy Research Explained" public event with FutureNeuro, attended by over 200 people on International Epilepsy Day. We also collaborated with Trinity College Dublin on a further public event on epilepsy research for the Festival of Neuroscience in April.

Three Epilepsy Ireland-funded projects continued throughout 2019.

Prof. David Henshall's study at RCSI on the role of microRNAs in the mechanism of the ketogenic diet is investigating whether microRNA levels in blood samples or other body fluids (urine, saliva) can predict which children will benefit most on the diet and aims to shed new light on how the diet works. This study was initially funded in 2016 under the HRB/HRCI Joint Funding scheme.

Prof. Gianpiero Cavalleri is investigating, also at RCSI, possible links between auto-immune epilepsy and the microbiome. This study was funded for three years from 2018, also under the HRB/HRCI Joint Funding Scheme.

We also continued to co-fund research at RCSI on the role of the Epilepsy Patient Portal in improving epilepsy health services. The study measures patient, carer and healthcare professional perspectives on the e-Portal, an e-health solution which allows epilepsy patients to access and interact with their own health records online. The project is funded by the HRB under the Applied Partnership Awards. €20,000 is being provided by Epilepsy Ireland as a knowledge-user.

EPILEPSY IRELAND
HAS INVESTED
OVER €1 MILLION
IN 13 PROJECTS
SINCE 2009 UNDER OUR
RESEARCH FUNDING
SCHEME

7th Research Funding call launched

In 2019, the Board approved the launch of Epilepsy Ireland's seventh call for funding proposals. A record 16 pre-applications were received by the deadline and by the end of 2019, a shortlisting process had been completed by the Research Review committee chaired by Prof. Martin Brodie which resulted in six applicants being invited to submit full applications. Applications of up to €50,000 p.a. for up to three years were invited and the process continues into 2020. In setting the objectives of the call, feedback was sought from EI members and service users and almost 100 people inputted into the process.

Other contributions to research

Other research communications activities during the year included the publication of our research newsletter for donors who support research funding and collaborating with FutureNeuro on the 'Epilepsy in English' website aimed at explaining epilepsy research in plain English for a public audience. See www.epilepsyinenglish.ie.

Epilepsy Ireland also supports Irish research in a number of non-financial ways. We highlight research volunteering opportunities to our service users. For example, in 2019, this included research at Queens University Belfast on the role that untrained dogs can have in predicting seizures. We also work with research teams as an official collaborator where possible. In 2019, this included the ongoing DCU Patient & Public Involvement (PPI) Ignite project; a HRB-funded study into the effectiveness of risk minimisation measures to prevent harm from teratogenic medicines in pregnancy; and a newly funded HRB proof-of-concept study which will look at the potential to link data from sources such as the epilepsy electronic patient record to other data sources like the PCRS to gain insights into disease progression, risks and resource utilisation. Epilepsy Ireland staff are also contributing to the various stages of the e-Portal project in our role as project knowledge-user.

Rachel Ashe spoke about the importance of research from a person with epilepsy's perspective to celebrate reaching our €1m milestone.



Epilepsy in English blog authors Gareth & Cristina have become regular features in our member's newsletter, explaining the latest developments in epilepsy research in plain English.



FUNDRAISING



Irish band Keywest took time out to support our Rose Week volunteers in Wexford.

We are reliant on the generous support of people across the country to provide services, raise epilepsy awareness, advocate and fund research and are very grateful to everyone who donated, volunteered or fundraised in 2019. We hope that you will continue to support us in the future so that we can continue our work in these areas.

Our annual fundraising events in 2019 included our national church-gate collections, Rose Week Appeal, Purple Day, the fundraising lunch with then Ireland Rugby Head Coach Joe Schmidt, our members raffle and the Time for a Break monthly draw.



B.J. Botha, Kathryn Thomas, Eva Ní Shuilleabháin & Joe Schmidt pictured at our fundraising lunch in May.

We are also thankful to our supporters who run their own events on our behalf like the annual Tour de Gaggs cycle and the Liane Deasy Memorial Swim. We also want to say a big thank you to our supporters who participated in the Women's Mini Marathon, the Dublin and Cork City Marathons and our popular Ancient East Peaks Challenge.

Purple Day was a huge success in 2019 both in terms of awareness-raising and fundraising. Almost 40 landmark buildings lit up purple and we had an abundance of coffee mornings and other creative events taking place in communities and places of work around the country.



A sea of blue filled the Cork Women's Mini-Marathon thanks to our fantastic volunteers!

We were also honoured to be the nominated charity at the 2019 EY Entrepreneur of the Year where a fantastic €20,000 was donated in support of our work.

Overall income from fundraising was €595,000 (2018: €946,000), which was in line with expectations, following an extremely successful previous year where income was boosted significantly by two large, one-off sources of income.



The EY Entrepreneur of the Year team presenting a cheque of €20,000 towards our work.

On this page, we feature just a few images of the wonderful fundraising activities from 2019. To see more, follow us on social media, and please consider making a donation or getting involved in our fundraising efforts in 2020. Your support is needed now more than ever as a result of the serious impact Covid-19 is having on our ability to raise funds from events and campaigns.

Visit www.epilepsy.ie for more information or to make a secure donation. You can also contact our Fundraising team at fundraising@epilepsy.ie



The Rose of Tralee Festival supported our 2019 Rose Week fundraising campaign.

Some of the brilliant volunteers who raised funds for Epilepsy Ireland climbing four 'Ancient East' mountains over the course of a weekend in 2019.



GOVERNANCE

The Epilepsy Ireland voluntary board of directors are committed to the highest standards of corporate governance and understand that this is a key obligation in ensuring best practice in the operation of the organisation's activities.

The board is comprised of 12 volunteer members (as at 31-12-2019) drawn from a variety of backgrounds and experiences and is responsible for the leadership, strategy and control of the organisation. Six directors stepped down from the board during 2019 following many years of service. These were: Prof Norman Delanty, Dr Michael Hennessy, Dr Brian McNamara, Dr Brian Sweeney, Dr Bryan Lynch and Mr Michael McLoughlin. Other changes during the year included the appointment of Ms Cathy Grieve as Chairperson, replacing Mr Mark Dowdall who served as Chair for six years. Ms Clare O'Dea was elected as Company Secretary to replace Ms Grieve.

Seven board meetings were held in 2019. Key board activities during the year included:

- Reviewed mid-point progress against the 2017-21 Strategic Plan.
- Establishment of a new Business Development & Sustainability sub-committee to advise the board on income generation strategies.
- Decisions taken to protect the organisation's financial position such as updated financial procedures, reserve designations and bank deposits.
- Board member training during the year included sessions on the Governance Code and attendance at the Charities Institute Bolder Board training in November.
- The President of the International Bureau for Epilepsy accepted an invitation to meet with the Board at its December meeting to discuss international priorities.

Epilepsy Ireland has achieved the Charities Institute Ireland 'Triple Lock' standard of full compliance with the Guidelines for Charitable Organisations on Fundraising from the Public; the Governance Code for the Community and Voluntary Sector; and preparing our financial statements in accordance with SORP for charities. The charity will comply in full with the Charity Regulator's Governance Code from 2020. Epilepsy Ireland has also attained PQASSO Quality Mark Level 1, the leading quality assurance system developed for the non-profit sector.

Finance & Audit sub-committee

The role of the sub-committee is to assist, support and advise the Board in the management and monitoring of the organisation's finances, business activities and strategic direction. It advises the board on matters relating to budgeting; monitoring of income and expenditure; financial audit; strategic planning; financial procedures and controls; risk; and utilisation of reserves. In 2019, the sub-committee met on seven occasions.

Other sub-committees

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 services. The Remuneration sub-committee has responsibility for setting the CEO's objectives and evaluating CEO performance. The new Business Development & Sustainability sub-committee will advise the board on income generation strategies and the long term financial sustainability of the organisation.

Board of Directors Meetings	February 4th	April 2nd	June 10th	July 23rd	September 2nd	October 22nd	December 2nd
Mr Mark Dowdall	√	√	√	x	√	√	√
Ms Cathy Grieve	√	√	√	√	√	x	√
Mr. Paul Kehoe	√	√	√	√	√	√	√
Mr Tony Caravousanos	√	x	x	√	x	x	√
Mrs Tessa Dagge	x	x	√	√	√	√	√
Ms. Mary Fitzsimons	√	√	x	√	√	x	√
Mr Derry Gray	x	√	√	√	x	√	√
Mr. Ambrose Kealy	√	√	√	x	√	√	√
Mr Michael McLoughlin	√	x	√			Resigned	
Ms Clare O'Dea	√	√	x	x	√	√	√
Ms Carol Saarsteiner	√	√	√	x	x	√	x
Mr Vincent Savino	x	x	x	x	x	x	x
Dr Joyce Senior	x	x	x	√	x	x	x

Dr Michael Hennessy, Dr Bryan Lynch, Dr Brian McNamara, Dr Brian Sweeney and Prof Norman Delanty resigned from the board during the year and did not attend any meetings.

Finance & Audit Subcommittee Meetings	January 29th	March 25th	May 28th	July 16th	August 27th	October 15th	November 25th
Mr. Michael Sheehy	√	√	√	√	√	√	√
Mr. Mark Dowdall	x	√	x	x	x	√	√
Mr. Paul Kehoe	√	x	√	√	√	x	√
Ms. Tessa Dagge	x	x	x	√	√	√	√
Mr. Tony Rhatigan	x	√	√	√	√	√	√
Mr. Declan Service	x	x			Resigned		
Mr. Derek Heffernan	√	x	√	√	x	√	√
Mr. Shane O'Brien			Not a member			√	√

FINANCIAL REPORT

In 2019, Epilepsy Ireland reported net incoming resources of €7,339 (2018: net outgoing resources, €137,562).

Income reduced to €1.7m in 2019 from €2.04m in 2018. This was in line with projections as 2018 included one-off unrestricted income from legacies and a one-year corporate partnership with Permanent TSB.

Expenditure was broadly in line with expectations totalling €1,728,249 (2018: €1.91m). €90,686 of unrestricted income was utilised to offset deficits in HSE-funded services (2018: €150,975).

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.

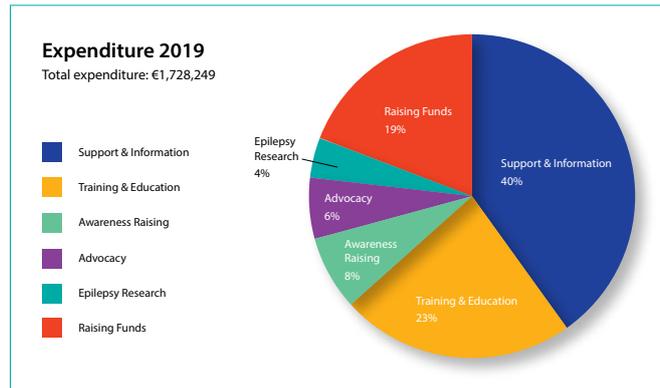
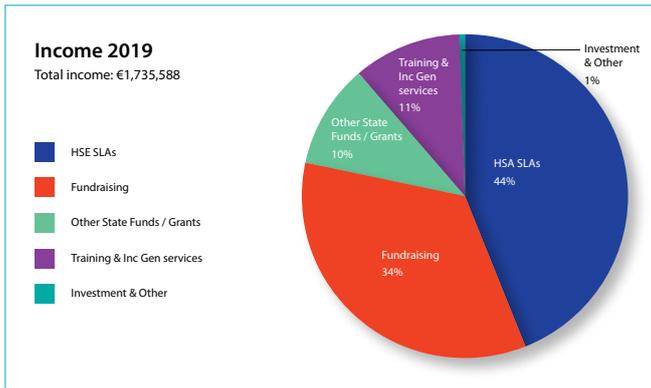
The full financial statements are available from epilepsy.ie or from info@epilepsy.ie.

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 2019.

	Restricted Funds	Unrestricted Funds	Total Funds	Restricted Funds	Unrestricted Funds	Total Funds
	2019	2019	2019	2018	2018	2018
	€	€	€	€	€	€
INCOME FROM:						
Donations and Legacies	12,500	350,357	362,857	17,970	680,984	698,954
Charitable Activities	942,646	188,564	1,131,210	896,298	159,069	1,055,367
Other Trading Activities	36,300	195,605	231,905	46,287	201,267	247,554
Investment Income	-	2,098	2,098	-	881	881
Other Income	-	7,518	7,518	-	43,293	43,293
Total	991,446	744,142	1,735,588	960,555	1,085,494	2,046,049
EXPENDITURE ON:						
Charitable activities	1,047,556	351,050	1,398,606	1,077,464	518,902	1,596,366
Raising funds	14,520	315,123	329,643	18,515	293,606	312,121
Total	1,062,076	666,173	1,728,249	1,095,979	812,508	1,908,487
Net income/ (expenditure) before taxation	(70,630)	77,969	7,339	(135,424)	272,986	137,562
Taxation	-	-	-	-	-	-
Net income/ (expenditure)	(70,630)	77,969	7,339	(135,424)	272,986	137,562
Transfers between funds	90,687	(90,687)	-	150,975	(150,975)	-
Net movement in funds	20,057	(12,718)	7,339	15,551	122,011	137,562
Total funds brought forward	47,107	1,403,572	1,450,679	31,556	1,281,561	1,313,117
Total funds carried forward	67,164	1,390,854	1,458,018	47,107	1,403,572	1,450,679



Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Balance Sheet
As at 31 December 2019

	2019 €	2018 €
Fixed Assets		
Tangible assets	146,383	132,764
Current Assets		
Stock	-	10,137
Debtors	130,683	101,579
Cash at bank and in hand	1,418,723	1,459,045
	1,549,406	1,570,761
Current Liabilities		
Creditors: Amounts falling due within one year	(237,771)	(252,846)
Net Current Assets	1,311,635	1,317,915
TOTAL NET ASSETS	1,458,018	1,450,679
FUNDS OF THE CHARITY:		
Restricted funds	67,164	47,107
Unrestricted Funds		
- General funds	924,900	762,323
- Designated funds	465,954	641,249
TOTAL FUNDS	1,458,018	1,450,679



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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

