



ANNUAL  
REPORT  
2020

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# 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 2020, we will set out how we have worked to meet each of these aims throughout the year.*



Best Practice in Transparency and Accountability

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.

## **Board of Directors**

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

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Mr Derek Heffernan  
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Mr Shane O'Brien  
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Prof. Norman Delanty  
Dr Patrick Dicker  
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Prof. David Henshall  
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Mary Fitzsimons  
Peter Murphy  
Tara Smith

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

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## **Remuneration sub-committee**

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## **Sustainability & Business Development sub-committee**

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

## **Staff**

### **Chief Executive**

Peter Murphy

### **Services**

#### **Director of Services**

Tara Smith

#### **Training Manager**

Paul Sharkey

#### **Training For Success Manager**

Maire Tansey

#### **Training For Success Facilitator**

Edel Feely

#### **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)

## **Fundraising, Communications and Administration**

### **Communications Officer**

Paddy McGeoghegan

### **Membership & Fundraising Officer**

Ashley Butler

### **Reception & Churchgate Collections**

Barbara Doyle

### **Fundraising Assistants**

Luke Meany  
Judith Kelleher

### **Finance Manager**

Andrew O'Dwyer

### **Executive Assistant**

Cathy Powell

## A MESSAGE FROM OUR CHAIRPERSON, CATHY GRIEVE



2020 is a year which will live long in the memory. Nobody could have predicted the challenges that our organisation would face over the course of the past year.

For many the year 2020 will be remembered for all the wrong reasons, but in other ways there were reasons to be hopeful and indeed proud of how resourceful and flexible we all can be during the worst of times.

One such example is how our dedicated team adapted rapidly to continue to provide vital supports to people with epilepsy and their families in the new online environment. We have been to the forefront in providing people with epilepsy the information they need during these uncertain times. Epilepsy Ireland took an active approach in ensuring that contact was initiated and maintained with some of the most vulnerable of our service users.

Having been involved with Epilepsy Ireland for several years now in a number of different roles at board level, I have never been prouder of my association with our organisation than over the

past year – and that is down to you; our members, volunteers and supporters.

While the restrictions have meant you have been unable to support us in the “traditional” way, you certainly have been more than willing to think of new ideas and challenges to support the work of Epilepsy Ireland, throughout a surreal year.

On behalf of the board of Epilepsy Ireland, I would like to thank you for your continuing support and assure you that despite the ongoing challenges due to the pandemic, our focus remains on achieving a society where no person’s life is limited by epilepsy.

I would also like to put on record my sincere thanks to our CEO, Peter Murphy, for his strong leadership and to all the staff team for their flexibility and dedication to work in changed circumstances. Thanks also to my fellow board members, who were available regularly, both as a full Board and individually to help navigate the stormy waters that were a feature of 2020.

While we are still some way from returning to “normal”, remember that one thing remains certain – we are still here for you.

## A MESSAGE FROM OUR CEO, PETER MURPHY



Thank you for taking the time to read about Epilepsy Ireland’s activities throughout 2020 – a year which none of us will ever forget.

When we first started to hear of ‘the coronavirus’ in early 2020, none of us could have imagined the changes and challenges that lay around the corner.

As I write this foreword to our Annual Report, the Epilepsy Ireland team have been working remotely for over a year. As a community-based organisation, this has required a re-imagining of how we continue to fulfil our mission, but the challenge has been met head on.

From the start, our priority has been to maintain our services in an online environment and to continue to support individuals and families living with epilepsy. For many, the pandemic has added further challenges to life with epilepsy – access to care, education and employment issues, mental health effects and seizure management are just a few of the challenges that have come to the fore as a result of the pandemic.

As well as supporting people through these challenges; our awareness raising and advocacy projects; training; and investment in research have all continued and each are outlined in the pages that follow.

Financially, Covid-19 has also had an impact on our work at Epilepsy Ireland. Fundraising and other income streams fell by 50% in 2020, but even in a time of great uncertainty, there was a tremendous response to our online campaigns and appeals and I want to thank all our donors and supporters who made the work outlined in this report possible.

We were also very grateful to receive a one-off allocation from the Government’s Stability Fund for charities which helped greatly to offset the impact of reduced fundraising income. While this cash injection may give the impression of a “normal” year financially, nothing could be further from the truth and Covid-19 will continue to leave its mark on our work and finances for the foreseeable future.

The dedication of our incredible staff team alongside the tireless efforts of our members and supporters has meant that despite everything which has happened, we remain firmly fixed on our vision of a society where no person’s life is limited by epilepsy.

We look forward to the brighter days that lay ahead. Thank you for your support in helping us to reach them.

# OUR YEAR IN WORDS

We are all familiar with these terms now, but in March 2020 they were all very new!

VIRTUAL EVENT

NEW NORMAL ONLINE FUNDRAISING

WEAR A MASK STAY SAFE

ADAPT #TOGETHER #HOLDFIRM

LOCKDOWN ADJUST SUPPORT

WE'RE STILL HERE

STRESS ANXIETY ZOOMING

CONTACT TRACING

REASSURANCE FOCUSED

QUIZ!

TEAMWORK

HERD IMMUNITY

BRIGHTER DAYS!

VACCINES

WASH AND GO

TEAMS

FLATTEN THE CURVE

REMOTE

# SUPPORT & INFORMATION

## Support and Information

Our mission is to achieve a society where no person's life is limited by epilepsy and at the centre of that mission is the support we provide for people with epilepsy and their families.

Epilepsy is very much a journey and we are there to offer advice and support to people with epilepsy and their families regardless of what stage of their journey with epilepsy they are at. This work is done by our team of 11 Community Resource Officers and our National Information Officer who between them cover the 26 counties of the Republic of Ireland from our 9 regional offices and our headquarters in Dublin.

Throughout 2020, we saw continued demand on our services which highlighted the importance of the work we carry out in communities across Ireland.

## COVID-19 Response

With the directive to work from home, this meant that all of our in-person events had to be cancelled due to public health guidelines. Our team worked quickly to ensure that we continued to offer vital supports to people with epilepsy and their families. This initial response focused on making contact with our most vulnerable service users and offering reassurance that we were still here to provide advice and support with their epilepsy. We also advised on what we knew about COVID-19 at that time.

Community Resource Officers also recorded short videos for sharing on social media to pass on contact details and to let our service-users know that we were still there for them for queries they may have. As the situation progressed and as more information became available, a new mini-site was developed on our website focusing on the issue of COVID-19 and epilepsy which covers subjects such as facemasks, managing your wellbeing and even some tips for exercise from home – amongst a whole host of other useful and relevant information.

Staff were also trained in the use of zoom which meant that supports could continue remotely with this developed further as the year progressed to offer group events across the country.

In addition to all the above, we have highlighted the public health messaging of the HSE and Department of Health throughout the year in an effort to ensure these important messages were reaching the people we support.

## Contacts

While the cancellation of all physical community, outreach and group events resulted in a drop in the overall number of service user contacts in 2020 (17,384 compared to 21,821 in 2019), there was a marked increase in individual (one-to-one) contacts with our service.

In total, we recorded 11,392 contacts (2019: 9,836) through phone, email and on-line platforms (Zoom, Teams, WhatsApp

etc.), highlighting the importance of our service remaining available throughout the crisis. It also reflects a growing need for more personalised and one-to-one support, as noted in previous years.

This was essential support to provide throughout 2020 as COVID-19 created many new challenges for people living with epilepsy. Some of the more common support queries included:

- The relationship between epilepsy and Covid-19 (risk of adverse outcomes, seizure risks associated with fever, impact of epilepsy medications on the immune system etc.)
- Responding to seizures and administering first aid/ emergency medication in a socially distant environment
- Access to medical services, concerns over continuity of supply of medications
- The effects of lockdown including increased social isolation which led to a range of mental and physical health implications. This has been a particular concern in a population already more prone to isolation and mental health issues, and through our services, we noted an increase in both the frequency and severity of these issues.
- Parents of children with epilepsy make up a large proportion of our service users and specific issues faced by parents included: caring for the child if they contracted Covid-19; monitoring of seizure activity; the impact on the child caused by the loss of routine, homeschooling and its effect on educational and developmental progress.
- The adoption of facemasks created initial difficulties for many people with epilepsy, concerned at the potential impact on breathing - hyperventilation is an established seizure trigger for some people.

Through this period, we also engaged with 2380 new service users. (2,774:2019)

## Service contacts by region 2020

	Individual	Group	Total
North West	789	307	1095
West	613	200	813
Mid-West	606	677	1283
South	1904	1096	3000
South-East	867	331	1198
East	5746	2949	8695
Midlands / North East	868	433	1300
<b>Total</b>	<b>11392</b>	<b>5992</b>	<b>17384</b>

## Events

While in-person group events could not happen for the vast majority of 2020, as the team and service users got more comfortable with the new normal, we were able to offer a range of remote supports to people with epilepsy and their families.

Some of these events focused on issues surrounding employment; education events focussing on both new adult and paediatric diagnoses, epilepsy awareness and joint events with other organisations such as the National Learning Network and Helium Arts.

In total, our team organised 59 events with 1,053 people attending – the majority of which took place online.

### Group Supports

We continued to offer group supports remotely throughout 2020. The new environment did take some getting used to for the regular attendees of our physical support groups but by year end, we had facilitated 43 local support group meetings (61: 2019); with specific groups offered for both parents with children with epilepsy and adults with epilepsy. 220 people attended these events.

### Epilepsy Specialist Nurse

Epilepsy Ireland are proud to fund a Registered Advanced Nurse Practitioner (RANP) post at Beaumont hospital, 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.

Early in lockdown, the RANP was redeployed to neurology wards and then moved to support the Epilepsy Nurse Line in Beaumont one day a week. 761 calls/emails were supported through this with 200 contacts with Beaumont patients. 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.

This role was vital in communicating information on our channels about COVID-19 from an Epilepsy perspective.

### Epilepsy Toolkits

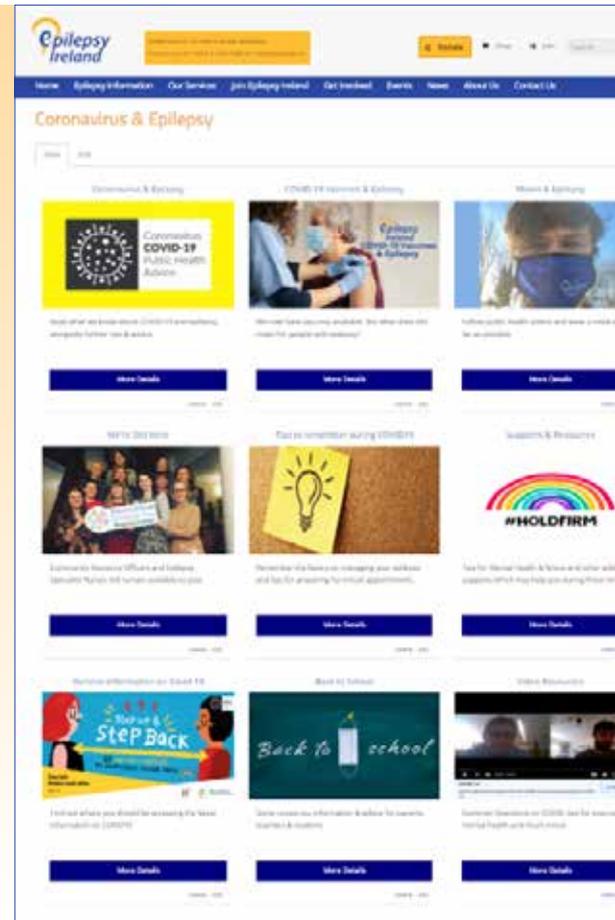
The Living Well with Epilepsy “Toolkit” is a core element of our service where we engage and support people with new and existing diagnoses. The main aim of the programme is to help people with epilepsy or parents of children with epilepsy to understand the condition and to provide them with the information needed to begin to self-manage their epilepsy. There were 213 sessions in 2020 with 313 participating in both individual and group sessions 2020. By the end of 2020, a full review to update the toolkit was also underway.

### Sláinetcare

In late 2019, Epilepsy Ireland received funding of €93,000 through the Slainetcare Integration Fund to deliver an education programme for people with a new diagnosis of epilepsy in conjunction with the HSE’s epilepsy service. This new service was designed to be delivered in group face-to-face settings and unfortunately was interrupted by Covid-19, requiring a redesign of the project. Live virtual sessions were organised with HSE Epilepsy Specialist Nurses and the

project was extended into mid-2021 to enable completion. This project also includes the development, in conjunction with the Department of General Practice at UCC, of a patient held epilepsy checklist/ consultation guide to maximise primary care appointments and work on this continued during 2020. The checklist will be launched in 2021.

*The mini-site which was developed on epilepsy.ie in response to COVID-19*



*Our Community Resource Officer Niamh Jones alongside all the CROs recorded messages to let everyone know that we were still available remotely throughout the pandemic*



*Dr. Liz O'Mahony from University Hospital Limerick speaking to an online meeting for parents of children with epilepsy*



# TRAINING & EDUCATION

## **Buccal Midazolam Training for Professionals.**

Since 2009, Epilepsy Ireland has been providing a training programme in Epilepsy Awareness and 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.

The training was adapted in response to COVID-19 in order to better facilitate online delivery of the programme. In "normal" times, the training is a full day training event for those in attendance. However, with delivery taking place online, this was amended to provide a streamlined version which allowed for accreditation for a shorter period of time with smaller numbers in attendance to allow for questions.

During 2020, 163 Epilepsy awareness and administration of BM courses took place (277: 2019) with 2,057 healthcare professionals and teachers trained (2,871: 2019).

## **Buccal Midazolam Training for Parents/Carers**

We also provide demonstrations for parents and carers in administering BM. In 2020, 43 individual epilepsy awareness and BM information sessions were delivered with 144 parents/caregivers attending (231: 2019).

Training for Success (TFS) is Epilepsy Ireland's one-year fulltime QQI Level 5 training programme first established in 1998. This joint initiative is based at the Institute of Technology Sligo and supported through funding from 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 formal educational and career aspirations.

Like all aspects of our service, Training for Success was adapted for online delivery and we had 11 students join the new intake of our course in September (10: 2019).. Sadly, our graduates from the 19/20 course were unable to have their graduation in person due to the restrictions but we look forward to seeing them all again when the circumstances allow.

## **Epilepsy Awareness for Education Providers**

Demand remained high from education professionals for our specific epilepsy awareness training for teachers and SNAs and other education professionals. While there was a reduction in numbers reached given the fact schools / colleges and childcare providers were closed for a significant period, we still delivered 129 talks in schools, preschools and other education settings with 2,463 people attending. (2019: 156; 4,659).

## **App & E-learning**

By the end of the 2020, we also began work on developing a new e-learning platform to enable longer-term structured online delivery of key self-management and information resources.

In addition to this, we also began work on the redevelopment of the Epilepsy Ireland smartphone App for IOS and Android. The app helps people with epilepsy to record features of their condition and set medication reminders. Both these projects are set to be completed and launched in 2021.



*TFS Student Debbie Kobe was one of the faces of our 2020 International Epilepsy Day campaign*



*After 22 years of the course, Training for Success got its own logo in 2020!*

# RESEARCH

Since 2009, Epilepsy Ireland has operated a Research Funding Scheme providing investment in high quality, high-impact Irish epilepsy research. Prior to 2020, over €1 million had been invested in 13 projects and in 2020, despite the financial uncertainties caused by the pandemic, two new projects were funded.

## **Impact of driving restrictions on people with epilepsy**

€15,000 was invested in a new study led by Prof Norman Delanty and Dr. Stephen Klaus of Beaumont Hospital and FutureNeuro/RCSI to examine the impact of imposed driving restrictions on people with epilepsy.

Driving restrictions can be one of the most significant aspects of an epilepsy diagnosis but their effect on the lives of people with epilepsy and families is not well documented. This study will examine patients' views on the restrictions, financial impacts, perceived social stigma, loss of employment and impacts on relationships. It will also look at alternative transport arrangements; the accessibility of the Free Travel scheme; the impact on people who drove professionally; and potential effects on the doctor-patient relationship.

This is an important study to Epilepsy Ireland and our members, addressing a key ongoing advocacy issue.

## **Epilepsy Mortality in Ireland study**

Up to €25,000 has been committed to a new study on epilepsy mortality led by Dr Yvonne Langan, St James's Hospital, Dublin in partnership with the Health Research Board (HRB). The study began in 2020 and will continue through 2021, subject to pandemic restrictions.

Using data from coroner records, the study will examine all deaths in people with epilepsy in 2019. Through HRB's existing infrastructure for accessing data held by coroners, the researchers will extract background information from records enabling them to determine the incidence of epilepsy-related deaths with particular emphasis on cases of sudden unexpected death in epilepsy (SUDEP).

This will be the first countrywide examination of SUDEP and epilepsy deaths in Ireland. It is hoped that the study will increase awareness of the issue; emphasise the need for access to expert care and treatments; and generate a new multilateral approach to reducing preventable epilepsy-related deaths.

## **Ongoing research projects**

The PISCES project at RCSI was originally funded by the Health Research Board in 2018, with €20,000 in co-funding from Epilepsy Ireland. PISCES seeks to investigate whether the development of an epilepsy electronic patient portal (e-Portal) could help foster a more person- and family-centred care approach between people living with epilepsy and their healthcare professionals. The study continued during 2020 with over 70 patients and carers involved in trialling the e-portal, as well as 20 epilepsy doctors, nurses and allied health professionals, including EI staff. The importance of e-health innovations like the e-portal was brought to the fore during Covid-19 and with the research

concluding in 2021, the focus will move to investigating how the e-portal can become embedded in clinical operations.

Prof. David Henshall's study at FutureNeuro on the role of microRNAs in the mechanism of the ketogenic diet was due to be completed in 2020. However, the project was impacted by laboratory closures at RCSI due to Covid-19, and an extension was granted by joint funders Epilepsy Ireland and the Health Research Board. The study aims to determine if microRNA levels in blood samples can predict which children will benefit most on the diet. €72,000 in total funding has been provided by Epilepsy Ireland.

Another FutureNeuro study led by Prof. Gianpiero Cavalleri on the potential links between auto-immune epilepsy and the microbiome also continued. 2020 was the final year of this jointly-funded Epilepsy Ireland/ Health Research Board 3-year project, but due to Covid-19 restrictions, this project is also being extended into 2021. In total, Epilepsy Ireland has invested €75,000 in this study.

In addition, Epilepsy Ireland provided a further research grant of €2,500 to Dr Neil Powell, Queens University Belfast towards his work investigating whether untrained (pet) dogs are able to predict epileptic seizures.

## **2019/2020 Research Funding call**

A record 16 pre-applications were received in the 2019/2020 funding call and six were shortlisted for full applications. In early 2020, an internal and external review process selected two proposals for submission to the HRB/ Health Research Charities Ireland Joint Funding Scheme. Unfortunately, neither project was selected for funding in an increasingly competitive process.

## **Other research developments**

Throughout 2020, we also worked with numerous researchers promoting research volunteering opportunities to our members and service users. This included participation in a number of studies investigating the impact of Covid-19 on people with epilepsy.

We also continued to collaborate with DCU on their PPI Ignite project, aiming to embed the concept of patient and public involvement (PPI) in research at the university.

We also continued our collaboration with FutureNeuro on the "Epilepsy in English" project, aiming to explain complex research concepts in plain English for a public audience.

*Dr. Yvonne Langan who will lead the Epilepsy Ireland funded study on Epilepsy Mortality.*



# EPILEPSY AWARENESS

## International Epilepsy Day

Despite the challenges that would follow, our 2020 got off to a hugely positive start with an internationally heralded #EpilepsyDay campaign taking place on February 10th.

The campaign aimed to bust some of the many myths that are associated with the condition, namely:

1. The myth that a spoon should be placed in a person's mouth during a seizure
2. The myth that there is only one type of seizure
3. The myth that a person should be restrained during a seizure
4. The myth that everyone with epilepsy is affected by flashing lights

The campaign received a phenomenal response, and this was down primarily to our fantastic volunteers Oliver, Debbie, Lorraine & Gerard.

With media appearances in the Irish Independent, Irish Times and RSVP alongside live appearances on Ireland AM and the Pat Kenny Show on Newstalk, we reached a huge audience. Social media posts on Facebook on the day alone reached over 400,000 people while we also had a billboard campaign running across the country for two weeks featuring our myth-busters! When reviewing the coverage and response the campaign received, we estimate that over 1,000,000 people were reached with our #EpilepsyDay campaign messages.

A critical aspect of ensuring this campaign had the reach that it did was due to the input and expertise of HAVAS Media who organised almost €250,000 of pro-bono media space to increase the reach of the campaign.

## National Epilepsy Week

National Epilepsy Week took place from May 18th – 24th. Epilepsy Ireland joined with our colleagues in the UK to explore the theme of #MoreThanSeizures. The theme was decided on by all organisations and aimed to explore the many "hidden" aspects of epilepsy as a condition that the wider public do not associate with epilepsy.

Issues such as employment, driving, mental health, stigma, the impact of valproate and the experience of being in an Epilepsy Monitoring Unit were shared by our volunteers Brenda, Nicola, Ruth, Theresa, Wayne, Lucy, Killian & Ralph.

Their personal testimonies - which were shared on our social media channels - showed the real-life experience of how epilepsy is so much more than seizures.

## SUDEP Action Day

SUDEP Action Day took place on October 23rd and encouraged people with Epilepsy to learn more about this rare but devastating aspect of epilepsy.

The day was also an opportunity to remember those who have sadly been lost due to SUDEP.

For our campaign, we shared personal testimony from Lucy Dineen, and the story of her son Robert who sadly passed away due to SUDEP.

We also announced details of new Epilepsy Ireland funded research investigating SUDEP and shared the findings of a survey we commissioned which highlighted that people with epilepsy want to know more about SUDEP and have open conversations with their healthcare team, even when they are perceived to be at low risk.

## Epilepsy Ireland Social Channels & Website

Our social media presence continues to grow and expand, increasing our reach and message even further. Facebook likes increased from 16,282 at the beginning of 2020 to 19,655 over the course of the year. Our other social channels on Twitter, Instagram and LinkedIn also saw increased growth throughout the year helping us to reach new audiences with our message.

Epilepsy.ie continues to be a trusted source of information for people with epilepsy with traffic to our site once again seeing an increase during 2020 and was particularly important source of information with specific information regarding COVID-19 and epilepsy.



*The images which formed our campaign proudly on display in Havas!*



*Lucy Dineen helped to increase awareness of SUDEP by telling the story of her son, Robert (left).*

# ADVOCACY

## Sodium Valproate

There was a major leap forward for families who have been impacted by Sodium Valproate (Epilim) in Ireland with the Minister for Health, Deputy Stephen Donnelly announcing in November that an inquiry will be held into the historical licensing and use of the commonly used epilepsy medication. Sodium Valproate is a very effective epilepsy medication but is associated with neurodevelopmental disabilities in 30-40% of children exposed to it in the womb and with congenital malformation in 10% of children. While evidence of these effects was emerging over many decades, significant measures to minimise the potential impacts were only put in place in Ireland and across Europe in recent years. The HSE estimate that approximately 1,250 children have been impacted in Ireland since 1975. Epilepsy Ireland and OACS Ireland (Organisation for Anti-Convulsant Syndrome) have been campaigning on the issue for many years and the announcement was warmly welcomed by families who have been affected and who deserve answers about how this was allowed to happen. The campaign, which continues into 2021 also focuses on the need to take further actions to minimise the risks in future and to ensure that children and families affected are appropriately supported by the State.

## Oireachtas Committee on Disability Matters

In November of 2020, Epilepsy Ireland made a submission to the Oireachtas Committee on Disability Matters focusing on two key issues that affect many of our members and their families: access to free travel for people who cannot drive due to seizures; and the need for more appropriate reasonable accommodations for students with epilepsy who are sitting state exams. While these are just two of many issues relevant to the epilepsy community, we believe that with political will and action, both can be resolved within the lifetime of this Dáil. Both issues were raised frequently by elected representatives at national and local level during the year and we are hopeful that further progress can be made in 2021.

## General Election 2020

Early in 2020, Epilepsy Ireland actively highlighted epilepsy issues to all General Election candidates and sought individual and party support on a number of key issues including improved epilepsy/ neurology services; access to new treatments; the need for action to reduce epilepsy-related deaths; free travel for people with epilepsy; reasonable accommodations in state exams and full implementation of the Oireachtas Health Committee's report on Sodium Valproate (2018). Dozens of candidates supported our manifesto and the time invested has greatly facilitated our representative efforts with those elected in February 2020.

## National Centre for Pharmacoeconomics Submission

In September, Epilepsy Ireland made our first submission to the National Centre for Pharmacoeconomics, in support of the reimbursement of Epidyolex, the first CBD medication licenced for use in epilepsy. The drug is indicated for use in two rare severe epilepsies – Lennox Gastaut Syndrome

and Dravet Syndrome. Our submission focused on the experiences of 10 families living with these conditions, the lack of effective existing treatment options and the impact that new proven treatments could have in reducing seizure frequency and improving quality of life. We hope that the drug will be made available on the Long-Term Illness Scheme and GMS in 2021.

## Other

Throughout the year, we continued to advocate for people with epilepsy through our membership of the Neurological Alliance of Ireland, Disability Federation of Ireland, the Wheel, IPPOSI, Charities Institute Ireland and Health Research Charities Ireland to further our goal of a society where no person's life is limited by epilepsy.

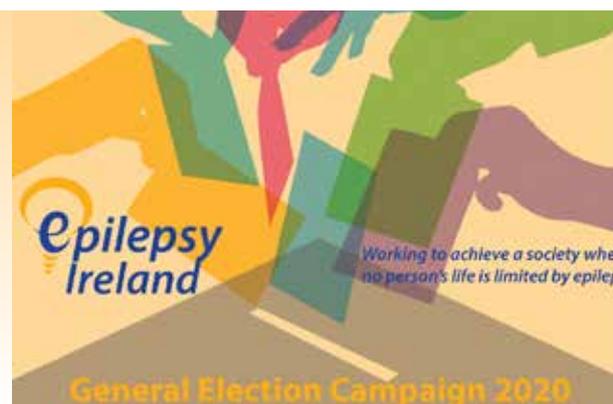
Internationally, we continued to engage with the International Bureau for Epilepsy and the International League Against Epilepsy on a range of issues, including ongoing efforts to develop a Global Action Plan on Epilepsy through the World Health Organization. A resolution on this was passed by the WHO's World Health Assembly in November 2020.

We maintained close working relationships with the medical community including through the HSE's National Epilepsy Clinical Care Programme, the Epilepsy Electronic Patient Record steering group, the Irish Epilepsy League and the FutureNeuro research centre. In addition, we continue to work to promote public and patient involvement in research with research institutions at DCU and RCSI and we also accepted an invitation to join the HPRA's patient forum, established in 2020.

*Karen Keely,  
Chairperson of  
OACS Ireland, the  
group of families  
working closely  
with Epilepsy  
Ireland on the  
sodium valproate  
campaign.*



*Epilepsy Ireland  
used the 2020  
General Election  
to highlight key  
issues within  
the epilepsy  
community with  
candidates.*



# FUNDRAISING

2020 saw a huge change to our fundraising model at Epilepsy Ireland with the onset of COVID-19. We are a community-based organisation and in “normal” years, our fundraising efforts reflect that with communities supporting our work through a range of local events like coffee mornings, non-uniform days, church-gate collections or special events at work. This was all lost during 2020 due to COVID-19 but, we can still boast some of the most wonderful volunteers who are steadfast in supporting our work. A total of €297,304 was raised in 2020 despite the difficult circumstances (€594,762: 2019).

## Facebook fundraisers

Facebook fundraisers are now essential to how we raise funds for our work and they came even further into focus in 2020. A total of 3.75% (€73,446.70) of our overall income came from these online fundraisers which mark a special occasion in a person’s life or a forum for friends and family to donate to a special challenge a person may be doing in support of our work. Please consider having a facebook fundraiser during 2021 in support of Epilepsy Ireland to mark your big day!

## Purple Day®

Purple Day was the first major casualty of our activities in 2020 due to the restrictions. The annual fundraising and awareness day was just a few days after the first lockdown was announced. With the lockdown, the day was essentially cancelled in a public sense with several wonderful events that were organised across the country no longer able to take place. With that, the day had to move online and the public certainly made sure it made an impact. A huge €25,171 was raised for our work which was phenomenal given the circumstances and set the tone for what was outstanding support for our work year-round.

## Rose Week

Much like Purple Day, our National fundraising week, Rose Week was entirely online during 2020 – although unlike Purple Day, we had a bit more time to prepare! The week featured testimony of some of our service users about how Epilepsy Ireland has helped them on their journey with epilepsy. This provided vital insights to the public on the work we do and why, which helped encourage the public to donate to our work.

One such testimony was that of Louise Young; who spoke about the support she received from Epilepsy Ireland during the lockdown. It made a huge impact and it was with great sadness that we learnt of Louise’s passing earlier this year (Jan 2021). She was a huge advocate for our work and will be sorely missed by all those who knew her.

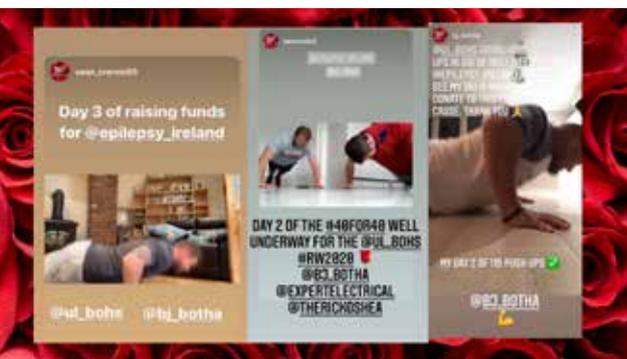
Alongside the testimonies of our services, we also had a number of challenges take place in support of our work during Rose Week. None more so was this evident than BJ Botha’s and UL Bohs’ 40,000 for the 40,000 challenge! Munster, Ulster & South Africa Rugby legend BJ has a young son with epilepsy and wanted to devise a challenge for Rose Week. He settled on doing 40,000 push-ups in recognition of the 40,000 people living with epilepsy in Ireland today. Throughout the week, all levels of UL Bohs aimed to hit the target and even had some help from the heavy hitters at Munster! They of course smashed their challenge, raising €4,690 but also created huge awareness of epilepsy as well.

## Expert Electrical

We were delighted to be selected as the Expert Electrical Charity partner in 2020! Expert are Ireland’s largest Electrical retailer and we formally announced our partnership in February 2020. Like most things to do with 2020, the plans we had initially devised didn’t all come to pass but Expert have been a constant source of support for our work. Expert’s stores have taken part in fundraising challenges such as #Challenge32 (raising €5,000); while Expert also provided exclusive discounts for our members during Rose Week. We also had Expert’s support for our annual raffle - with the top prize being sponsored by Expert which saw a huge increase in ticket sales. The raffle raised €13,280. All in all, it has been wonderful have the support of Expert throughout 2020 and is something we look forward to continuing in 2021.

## Thank YOU!

There are far too many individual efforts to mention on this short overview. We are not exaggerating when we say that mountains have literally been scaled in support of our work. Without this vital support, what we do would not be possible and our members & supporters have gone above and beyond during 2020 in the most difficult of circumstances. Thank YOU!



*Some of the UL Bohs team getting their push-ups in!*



*The EI and Expert team launching our partnership - before the days of social distancing.*

# 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.

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 Charities Governance Code; and preparing our financial statements in accordance with SORP for charities. We have also attained the Trusted Charity Quality Mark Level 1 (formerly PQASSO).

## Board of Directors

The board is comprised of 13 volunteer members (as at 31-12-2020) drawn from a variety of backgrounds and experiences and is responsible for the leadership, strategy and control of the organisation.

There were no resignations from the board during 2020. Mr Paul Fahey was co-opted to the Board during the year and was later elected to a four-year term at the AGM. Paul is a qualified pharmacist and health informatics expert. He is also a qualified Company Director holding a Diploma in Company Direction from the Institute of Directors. He has been a pharmacy owner for 25 years and served as the President of the Pharmaceutical Society of Ireland from 2011-2013. Full board member profiles can be viewed at [epilepsy.ie](http://epilepsy.ie).

Nine board meetings were held in 2019, eight of which were held remotely. Responding to the challenges caused by the pandemic were the board's key priority in 2020. During the year, the board:

- Closely monitored the organisations risk profile and risk register and agreed to review the register at least twice per annum from 2020 onwards.
- Revised the organisations research funding plans in light of the emerging Covid-19 pandemic.
- Approved, amended and monitored the organisation's

response to the pandemic especially in the area of service provision and the management of income and expenditure. Agreed to reduce senior management salaries/ hours temporarily due to uncertainty caused by pandemic.

- Availed of state supports including the Temporary Wage Subsidy Scheme and the Stability Fund for charities.
- Agreed to apply for certification under the IQ Quality standard in 2021.
- Completed a board performance review and adapted a number of new proposals aimed at improving the effectiveness of the board's functioning.
- Reviewed operational plan and budget for 2021 but delayed approval until early 2021 in order to better understand the changing Covid-19 situation and the State's vaccination strategy.

## Finance & Audit sub-committee

The role of the Finance & Audit 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. 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. In 2020, 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 Business Development & Sustainability sub-committee advises the board on income generation strategies and the long term financial sustainability of the organisation. Membership of these sub-committees is available on [epilepsy.ie](http://epilepsy.ie).

Board of Directors Meetings		Feb 4th	Mar 30th	Apr 20th	May 26th	July 6th	Sept 1st	Oct 19th	Dec 8th	Dec 15th
Ms. Cathy Grieve	Chairperson	√	√	√	√	√	√	√	√	√
Ms. Clare O'Dea	Honorary Secretary	√	√	√	√	√	√	√	√	√
Mr. Paul Kehoe	Treasurer	√	√	√	√	√	√	x	√	√
Mrs. Tessa Dagge	Director	√	x	x	√	x	√	x	√	√
Mr. Derry Gray	Director	√	√	√	√	√	√	√	x	x
Ms. Carol Saarseiner	Director	√	√	√	√	x	x	√	x	√
Mr. Tony Caravouanos	Director	√	√	√	x	√	√	√	√	x
Mr. Mark Dowdall	Director	√	√	√	√	√	√	√	√	√
Ms. Mary Fitzimons	Director	x	√	√	x	√	√	√	√	√
Mr. Ambrose Kealy	Director	√	√	√	√	√	√	√	√	√
Dr. Joyce Senior	Director	x	√	√	√	√	x	√	√	x
Mr. Paul Fahey	Director	Not a member	√	√	√	√	√	√	√	√

Vincent Savino was unable to attend any board meetings in 2020 due to health reasons

Finance & Audit Subcommittee Meetings		Jan 28th	Mar 24th	May 19th	June 30th	Aug 25th	Oct 13th	Nov 24th
Mr. Michael Sheehy	Chairman	x	√	√	√	√	√	√
Mr. Mark Dowdall	Member	√	√	√	√	x	x	√
Mr. Paul Kehoe	Treasurer	√	√	√	√	√	x	√
Mrs. Tessa Dagge	Member	x	x	√	x	√	x	Not a member
Mr. Tony Rhatigan	Member	√	x	√	√	√	√	√
Mr. Derek Heffernan	Member	√	√	√	√	√	√	√
Mr. Shane O'Brien	Member	x	√	√	√	√	√	√
Ms. Cathy Grieve	Member	√	√	√	√	√	√	√

# FINANCIAL REPORT

In 2020, Epilepsy Ireland reported net incoming resources of €138,771 (2019: net incoming resources, €7,339). Income increased to €1.9m in 2020 from €1.7m in 2019.

This was mainly due to a grant of €258,310 from the Department of Rural and Community Development Stability Fund for charities, an initiative aimed at reducing the impact of lost fundraising caused by the pandemic. Overall fundraising and earned income fell by 50% in 2020. Income also includes €249,075 in non-cash donations representing media and advertising services donated to the charity for our #EpilepsyDay campaign.

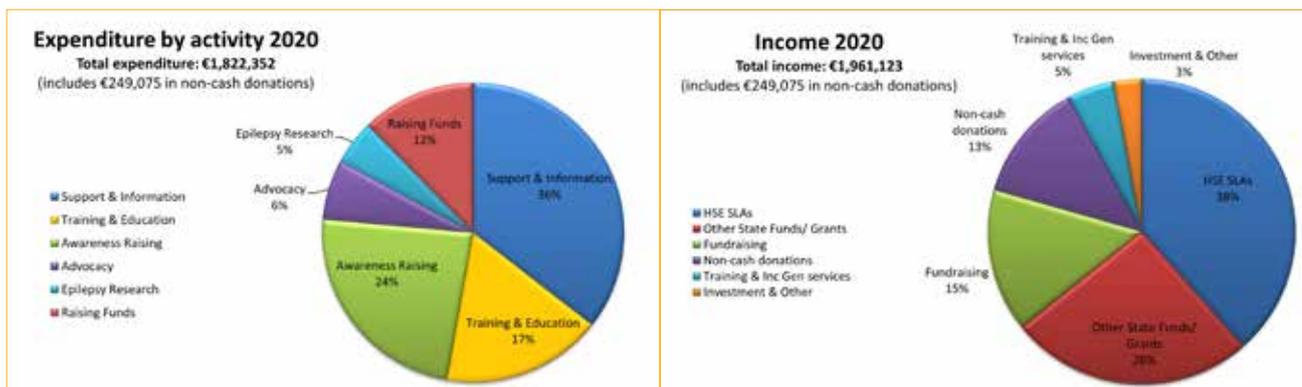
Expenditure remained in line with expectations totaling €1,822,352 (2019: €1.72m). This includes the recognition of €249,075 of non-cash expenditure on #EpilepsyDay. It also includes €68,918 of unrestricted income utilised to offset deficits in HSE-funded services (2019: €90,686).

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](http://epilepsy.ie) or from [info@epilepsy.ie](mailto: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](http://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 2020.

	Restricted Funds 2020 €	Unrestricted Funds 2020 €	Total Funds 2020 €	Restricted Funds 2019 €	Unrestricted Funds 2019 €	Total Funds 2019 €
<b>INCOME FROM:</b>						
Donations and Legacies	252,545	190,628	443,173	12,500	350,357	362,857
Charitable Activities	1,161,238	218,667	1,379,905	840,832	290,378	1,131,210
Other Trading Activities	27,342	75,864	103,206	36,300	195,605	231,905
Investment Income	0	3,453	3,453	0	2,098	2,098
Other Income	0	31,386	31,386	0	7,518	7,518
<b>Total</b>	<b>1,441,125</b>	<b>519,998</b>	<b>1,961,123</b>	<b>889,632</b>	<b>845,956</b>	<b>1,735,588</b>
<b>EXPENDITURE ON:</b>						
Charitable activities	1,290,529	308,155	1,598,684	945,742	452,864	1,398,606
Raising funds	86,270	137,398	223,668	14,520	315,123	329,643
<b>Total</b>	<b>1,376,799</b>	<b>445,553</b>	<b>1,822,352</b>	<b>960,262</b>	<b>767,987</b>	<b>1,728,249</b>
<b>Net Income/(expenditure) before taxation</b>	<b>64,326</b>	<b>74,445</b>	<b>138,771</b>	<b>(70,630)</b>	<b>77,969</b>	<b>7,339</b>
Taxation	-	-	-	-	-	-
Net Income/(expenditure)	64,326	74,445	138,771	(70,630)	77,969	7,339
Transfer between funds	68,918	(68,918)	-	90,687	(90,687)	-
<b>Net movement in funds</b>	<b>133,244</b>	<b>5,527</b>	<b>138,771</b>	<b>20,057</b>	<b>(12,718)</b>	<b>7,339</b>
<b>Total funds brought forward</b>	<b>67,164</b>	<b>1,390,854</b>	<b>1,458,018</b>	<b>47,107</b>	<b>1,403,572</b>	<b>1,450,679</b>
<b>Total funds carried forward</b>	<b>200,408</b>	<b>1,396,381</b>	<b>1,596,789</b>	<b>67,164</b>	<b>1,390,854</b>	<b>1,458,018</b>



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

Balance Sheet  
As at 31 December 2020

	2020	2019
	€	€
<b>Fixed Assets</b>		
Tangible assets	<b>143,467</b>	146,383
<b>Current Assets</b>		
Stock	-	-
Debtors	<b>191,416</b>	130,683
Cash at bank and in hand	<b>1,443,251</b>	1,418,723
	<b>1,634,667</b>	1,549,406
<b>Current Liabilities</b>		
<b>Creditors: Amounts falling due within one year</b>	<b>(181,345)</b>	(237,771)
<b>Net Current Assets</b>	<b>1,453,323</b>	1,311,635
<b>TOTAL NET ASSETS</b>	<b>1,596,789</b>	1,458,018
<b>FUNDS OF THE CHARITY:</b>		
Restricted funds	<b>200,408</b>	67,164
Unrestricted Funds		
- General funds	<b>858,359</b>	924,900
- Designated funds	<b>538,022</b>	465,954
<b>TOTAL FUNDS</b>	<b>1,596,789</b>	1,458,018



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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.



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



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