ANNUAL REPORT 2017

epilepsy Ireland

EPILEPSY IRELAND IN 2017

Epilepsy Ireland supports and represents approximately 37,000 people with the condition through our offices in Dublin, Cork, Dundalk, Galway, Kerry, Kilkenny, Letterkenny, Limerick and Tullamore as well as our Training For Success course at IT Sligo.

Service Users

2,132
new service users

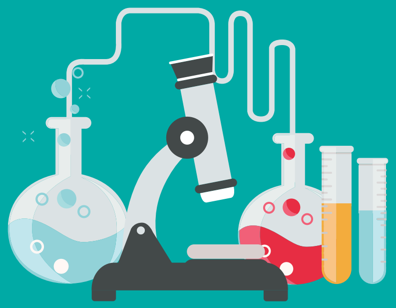
Services

There were
20,156
individual contacts
an increase from
19,460
in 2016

National Conference

Our National Conference was attended by **145 members** from all areas around the country

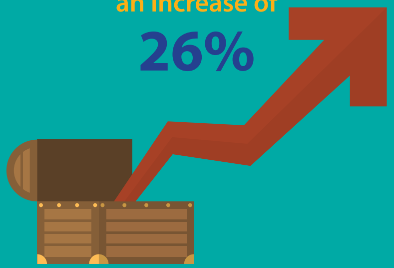
Research



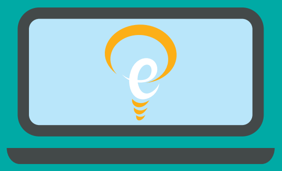
Since 2009, Epilepsy Ireland has invested over
€920,000
into nine Irish research projects

Training

1,863
people received training in 2017 as compared with the previous year's
1,571,
an increase of
26%



Communications



Epilepsy Ireland's website (epilepsy.ie) received
92,190
sessions in 2017 compared to
81,737
in 2016.

www.facebook.com/epilepsy.ie @epilepsyireland
www.epilepsy.ie **Email:** info@epilepsy.ie

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Our Vision

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

Mission Statement

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

- Providing support and information services
- Communicating, raising awareness and advocating about epilepsy
- Providing training and education
- Undertaking and supporting epilepsy research
- Raising the necessary funds for our work
- Operating a stable, transparent and accountable organisation meeting best practice standards

A MESSAGE FROM

Mark Dowdall, Chairman

I am pleased to present Epilepsy Ireland's Annual Report for 2017, which highlights our work and achievements as we strive to meet the needs of the 37,000 people with epilepsy and their families in Ireland. In this review, we outline just some of the achievements of the year across our key areas of work including support services, training, research, awareness raising and advocacy.

2017 was the first year of our five-year Strategic Plan which has been developed with input from members, service users, volunteers, health professionals and staff. The Plan is ambitious, seeking to protect existing services and activities, while also developing in new directions to ensure we continue to meet the needs of our service users and members.

As we embark on implementing our plans, we understand that as a registered charity, the question of 'how we do our work' is every bit as important as 'what we do'. We are committed to maintaining a focus on quality and good governance across everything we do, and in 2017, we formally adopted the Statement of Guiding Principles for Fundraising. We also worked towards full compliance with the Governance Code for Community, Voluntary and Charitable Organisations and prepared for re-certification under the PQASSO quality standard for charities. We also undertook a full review of our governing documents and in November, a new Constitution was adopted by our members which will strengthen the organisation's governance and administration into the future.

With these strong foundations, we look forward to building on over five decades of experience in supporting and representing people with epilepsy and their families. As a small organisation, our people are vital in achieving this and I want to thank my fellow voluntary board members and sub-committee members for their continuing time, expertise and passion for the cause of epilepsy. Thank you also to our dedicated management and staff team around the country, who continue to ensure that the best possible outcome is delivered for every euro spent.

Most importantly of all, I want to extend my thanks and appreciation to the thousands of people who support the work of Epilepsy Ireland by volunteering, donating or by being a member of the organisation. The work and impact outlined in this report would not be possible without your support and I hope that you will continue to invest in our ambitious vision of a future in which no person's life is limited by epilepsy.

Peter Murphy, Chief Executive

It is my pleasure to report on another busy and successful year at Epilepsy Ireland, though one which has also been challenging.

Our support services are the core of our work. These include one-to-one support, outreach services, educational programmes, self-management programmes and many other seminars and events. For the third year in succession, demand for these services increased in 2017 as we recorded 20,156 individual contacts. This represents a 4% increase from 2016, and a 37% increase from just three years ago. We supported 3,175 unique individuals, also an increase on previous years. Much of the growth is due to the success and impact of programmes such as STEPS, Innerwise and Living Well with Epilepsy and to strong links with epilepsy health services nationwide.

Another important service which continues to grow is our training programme in Epilepsy Awareness and the Administration of Buccal Midazolam for health and allied health professionals. 188 training courses were provided in 2017 with 1,835 people attending the courses, up from 152 courses and 1,571 trainees in 2016. Other noteworthy achievements for the year included the upgrading of our Training For Success one-year programme at IT Sligo to a QQI/ FETAC Level 5 course; focusing our awareness activities on the important issue of epilepsy in the workplace and providing effective representation on issues such as health service development and sodium valproate risk. We also continued to fund Ireland's only Epilepsy Transition Nurse Co-ordinator post, provided research grants for two important new projects and launched a new research call which will take total investment to over €1m in the past decade.

While these are all welcome developments, meeting and resourcing increased demand remains a challenge, especially in an environment of static HSE funding. Despite a growth in fundraising in recent years, we reported a net expenditure of €274,119 in 2017, and it is clear that a big challenge in the years ahead will be securing the additional income needed to implement our Strategic Plan. Our supporters and volunteers are more important now than ever and I want to thank every one for enabling our work in 2017.

Our staff team and volunteers also deserve great credit for building the reach and the impact of Epilepsy Ireland, not just those involved in providing services and training but also those who raise funds and provide administrative supports. Thank you to all of the team for making 2017 such a positive, successful year.

WHAT IS EPILEPSY?

Epilepsy is a general term used for a group of disorders characterised by recurrent, unprovoked seizures. Seizures are episodes of abnormal electrical activity in the brain that briefly alter a person's consciousness, movements or actions. How a seizure affects an individual will depend on the area of the brain in which the seizure originates. Partial seizures initially affect only one part of the brain and these can be 'simple' (consciousness is not affected) or 'complex' (consciousness is affected). If both hemispheres of the brain are affected from the outset, these are called generalised seizures, and involve the loss of consciousness. About 1 in every 20 people will have a seizure at some time during their lives.

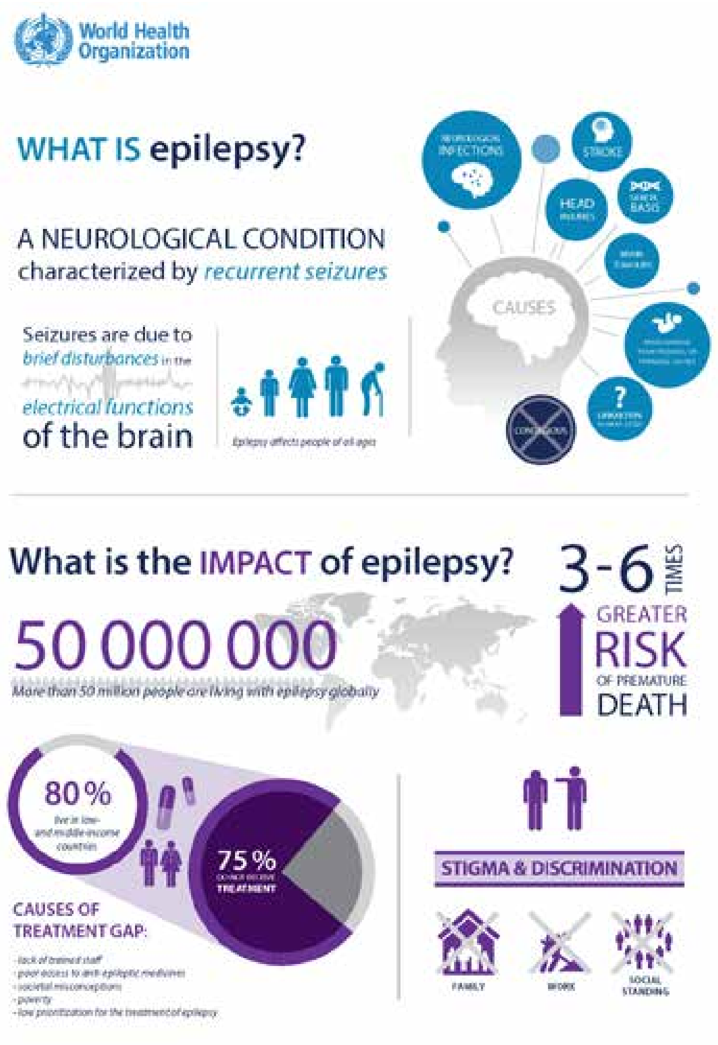
Epilepsy is one of the most common neurological conditions. Worldwide, more than 50 million people live with epilepsy. In Ireland, 37,000 people over the age of five have epilepsy and there are an estimated 1,300 - 2,100 new diagnoses each year. It can affect people of all ages, but is more prevalent in children, adolescents and the elderly. It is also more common in people with an intellectual disability. Common causes include head injuries, strokes, brain infections, birth defects and genetic conditions like tuberous sclerosis. Genetic mutations are also known to play a role in some cases. However, in about 60% of cases, no specific cause can be identified. Epilepsy is a treatable condition and the majority of people can become seizure-free thanks to medications or in some cases through surgical intervention. However, Epilepsy Ireland estimates that there are at least 10,000 - 15,000 people in Ireland living with uncontrolled seizures. For this group in particular, the consequences of an epilepsy diagnosis can be long-lasting and significant. It can affect the person's education, employment, psychological and social functioning, self-esteem and independent living.

People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications, and for many, the social stigma that can be associated with it. In addition to the impact that epilepsy can have on the person with epilepsy, it can also cause serious psychological, social and economic consequences for their families and carers.

People with epilepsy also have a higher risk of mortality than the general population. There are an estimated 130 epilepsy-related deaths in Ireland each year, about half of which are due to SUDEP (Sudden Unexpected Death in Epilepsy). SUDEP is still not fully understood but it is more common in young adults, in males, in those with uncontrolled seizures, and those with generalised seizures.

The financial cost of epilepsy is also significant. The total annual direct and indirect cost of epilepsy in Europe is estimated at €15 billion.

Epilepsy health services have historically been neglected in Ireland, a situation which has changed in recent years thanks to the work of the National Epilepsy Clinical Care Programme. The programme aims to improve access to expert care in Ireland and to improve the quality of that care. In recent years, it has been responsible for the introduction of a range of standard operating procedures, pathways for seizure management in the emergency department and has secured 20 new Advanced Nurse Practitioner positions dedicated to epilepsy care.



SUPPORT AND INFORMATION

Overview

Every year our services team deal with thousands of contacts in our individual work and group programmes. We offer a range of support services including one-to-one support, outreach services, regional and online support groups, educational programmes, group-based self-management programmes, a nurse-led helpline and a range of seminars, events and publications. Services are provided by a network of 11 Community Resource Officers (CROs) based in Dublin, Cork, Galway, Limerick, Kilkenny, Killarney, Tullamore, Letterkenny and Dundalk in addition to the Information Officer, Community Epilepsy Specialist Nurse, Transition Nurse Co-ordinator and overseen by the Deputy CEO/ Director of Services. Three new CROs were recruited in 2017 due to retirements.

For the third year in succession, demand for our services increased in 2017. There were 20,156 individual contacts with our services (an increase from 19,460 in 2016, 17,846 in 2015 and 14,750 in 2014). 9,750 of these contacts were on a one-to-one basis via our CROs, Information Officer, Training Manager and Epilepsy Nurses (2016: 8,577). We also supported 3,175 unique individuals 2016: 3,302) including 2,132 new service users (2016: 2,129).

In 2017, we continued to provide support to hospital epilepsy services, provided outreach to hospitals and accepted referrals from many of the country's Epilepsy Specialist Nurses, Neurologists and Paediatric Neurologists.

Service User analysis 2017

	Existing Service Users	New Service Users	Total Service Users
Person with epilepsy	393	477	870
Parent of child	330	456	786
Family/carer	52	162	214
Professional	176	469	645
Other	92	568	660

Regional Statistics 2017

	Total	Individual	Group
North-West	1376	703	673
Mid-West	1424	790	634
South (Killarney)	1268	645	623
South (Cork)	2229	759	1470
South-East	1399	512	887
Midlands	1061	660	431
North-East	1196	472	724
West	1183	602	581
East	7253	3645	3608

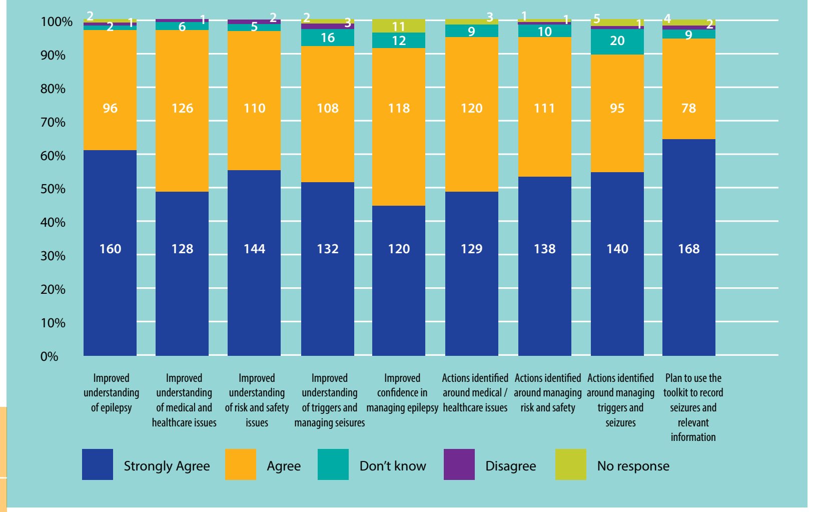
Education and Self-Management

A total of 488 people took part in our Living Well With Epilepsy 'toolkit' programme (2016: 397) designed for people with a new diagnosis and parents of newly diagnosed children. The toolkit includes crucial information such as seizure management charts, medication management section and first aid for seizures information. Over 1,500 service users have availed of this service since 2014.

There were 9 STEPS group-based self-management programmes for adults (2016:11) and 5 Parents STEPS Programmes (2016: 8). 'STEPS' stands for Support and Training in Epilepsy Self-management and enables people to learn more about their epilepsy and become experts in their own condition. Courses are delivered in a group setting typically lasting over 6 weeks. Since the programme was introduced in 2015, 27 courses have been delivered with over 200 participants.

In 2017, a new group-based advanced self-management programme called INNERWISE was rolled out across the country. Originally piloted in Dublin in 2016, the programme focuses on improving mental health and wellbeing, managing stress and developing life management skills through tools that include meditation and mindfulness. 10 programmes were held in 2017 supporting 93 participants. Additionally, there were also 66 support group events and 19 online support groups. Unfortunately, our online support group service was suspended in April 2017 due to the closure of the service provider.

Living Well With Epilepsy Toolkit Evaluation



Outcomes From our Education & Self-Management programmes

Evaluations of the Living Well With Epilepsy; STEPS and Innerwise programmes were conducted during the year, including quantitative and qualitative measures. Among the findings were:

- The vast majority of people who took part in the Living Well toolkit programme reported positive improvements across all parameters assessed (see graph above)
- STEPS participants reported a 35% increase in their knowledge and understanding of epilepsy, a 33% increase in their self-management skills and a 23% improvement in wellbeing
- Outcomes from the Parents STEPS programme were extremely positive with over 70% increases reported on a wide range of measures including understanding of epilepsy, managing seizures and communicating with their child about epilepsy
- Initial data from Innerwise found that 88% had improved feelings of wellbeing, 65-68% reported improvements on mental health measures and 80% reported a more positive outlook in relation to their epilepsy

Working with Younger People

A key strategic objective is to develop additional services to support children and teenagers with their epilepsy. In 2017, the annual family fun day took place in July at Fort Lucan, Dublin. Additionally, the helpline for teens and their parents, launched in 2016, continued through 2017. The service is managed by the Epilepsy Transition Nurse Co-ordinator, a post funded by Epilepsy Ireland across Dublin's three paediatric hospitals. The Transition Nurse is working to develop new best practice pathways for teenagers with epilepsy transitioning from children's to adult's services.

Seizure the Day

One of the most significant and innovative projects undertaken in 2017 was the 'Seizure the Day' film. Run in partnership with Helium Arts throughout the year, the project involved over 40 young adults with epilepsy via four regional workshops and a 5-day 'film camp' in the writing, acting, filming and the production of a fictional film about epilepsy inspired by their own experiences. The film along with a 'making-of' documentary was screened at the Irish Film Institute in October and feedback from participants and their families about their involvement has been excellent.

2017 National Epilepsy Conference

The 2017 National Epilepsy Conference took place in Sligo in September with over 145 people attending to learn about the latest developments in epilepsy care from 10 expert speakers. The speakers included Dr. Bryan Lynch, Dr. Kevin Murphy and Dr. Andrea Higgins, who led the session presenting the 'Top 10 things you should know about your epilepsy'. This was followed in the afternoon by workshops for parents of children with epilepsy and for adults with epilepsy. The conference continues to be Epilepsy Ireland's most important annual event and brings people together from all over the country to share experiences about the condition.

Information Resources

We undertook a full review of our epilepsy information materials in 2017 which resulted in the publication of a new range of resources including 'Epilepsy Explained', 'Safety & Seizures' and 'Epilepsy & Driving'. This completes a new suite of resources and provides us with a very extensive set of up-to-date and accurate resources for our service users.

A new version of the Epilepsy Management iPhone app was launched in February. The app aims to support people with epilepsy and parents of children with epilepsy to record information about their seizures (including video), identify potential triggers and seizure patterns, set important reminders, send emergency texts, organise medical appointments, measure missed medications and collect important data on their epilepsy.

Filming at IMMA with filmmaker Roisin Loughrey.

A packed room for the 2017 National Conference in the Clayton Hotel, Sligo.

AWARENESS AND ADVOCACY

International Epilepsy Day 2017

To mark International Epilepsy Day, Epilepsy Ireland used the day to focus on awareness of the condition in the workplace. The day received widespread local and national media coverage which included Epilepsy Ireland Patron, Rick O'Shea discussing his condition on RTE One's 'Today Show with Maura and Daithi'. On social media, International Epilepsy Day was one of Ireland's top trends on Twitter as people tweeted their support by taking a selfie for #EpilepsyDay. Continuing the theme, Epilepsy Ireland also published a new information resource for employers on epilepsy in the workplace addressing many of the common concerns and questions employers often have and aiming to reduce the myths and misunderstandings that can surround the condition.

Maura Derrane wears her Rose on RTE's Today Show to mark International Epilepsy Day which featured Epilepsy Ireland Patron, Rick O'Shea.

#iseebeyound

In February, ahead of International Epilepsy Day, Epilepsy Ireland and brain-injury charity Headway collaborated for the second year on the 'I See Beyond' (iseebeyond.ie) campaign highlighting the issue of hidden disabilities in the workplace. This was in response to data from the 2016 campaign which found that 7 in 10 people would not feel comfortable telling their employer they had a hidden disability and 9 in 10 employees in Ireland felt their workplace lacked awareness of hidden disabilities. A series of short videos were produced to highlight examples of how employees with epilepsy and acquired brain injury can contribute in the workplace as equals. The campaign also featured the National Hidden Disability Awards to honour and recognise employers who displayed excellence in supporting people with hidden disabilities. Brent Pope presented the awards in August with Hays plc crowned as overall winners. Additionally, a national survey of 1,000 members of the public conducted by Amárach Research showed the positive impact of the I See Beyond campaign with an increase of 36% of people compared to 2016 who would feel comfortable telling their employer they have a hidden disability. The campaign also received media coverage which included the Sunday Times and TV3.

Purple Day

For the first time in 2017, Epilepsy Ireland participated in an international grassroots effort dedicated to increasing awareness about epilepsy on March 26th. On Purple Day, people in countries around the world are invited to wear purple and host purple themed events in support of the condition. Over 30 landmarks throughout Ireland turned purple for the day which included the Convention Centre and Blackrock Castle. There was also significant support for the day on social media as hundreds of Epilepsy Ireland supporters shared purple images online.

In 2017 our Facebook 'likes' increased to nearly

12,000

Rachel Ashe, Philip Bourke and Arlene Sheridan of Hays plc pictured at the Hidden Disability awards ceremony.

The Convention Centre was one of 30 landmarks throughout Ireland turned purple for Purple Day.

National Epilepsy Week 2017

To mark National Epilepsy Week (May 15th-19th), Epilepsy Ireland announced results of a survey conducted among people with epilepsy on their experience of the condition within the workplace. A similar survey had been conducted in 2012 and it was very encouraging to see that 58% of respondents now felt comfortable in telling their employer and colleagues about their epilepsy (compared to 44% in 2012) and that just 33% found that their employer's/colleagues' attitudes changed following disclosure (compared to 50% in 2012). However, significant work remains to be done on raising epilepsy awareness, with almost one third of respondents reporting discrimination and just half of respondents feeling there is enough support in the workplace.

SUDEP Action Day

International SUDEP (Sudden Unexpected Death in Epilepsy) Action Day took place on October 23rd and Epilepsy Ireland took the opportunity to raise awareness of sudden death in epilepsy and to highlight risks and risk-management. We also undertook a survey of over 300 people with epilepsy to understand more about SUDEP awareness and about communications on the subject between patients and health professionals. Over 40% of participants were not aware of SUDEP before they took the survey but importantly, the vast majority indicated a preference for being told about the risks as early as possible after diagnosis, regardless of the perceived risk. The findings challenge traditional assumptions about SUDEP communications and we hope that they will kick-start a new conversation on the issue in Ireland. Awareness of SUDEP increased significantly in 2017 due to fundraising efforts of Mark Early who hosted various events in memory of his wife Liane. Mark also worked passionately throughout the year to highlight SUDEP in the media.

Online and social media

In 2017 our Facebook 'likes' increased from 10,300 in 2016 to nearly 12,000 while our Twitter followers also grew past 3,400. As the power of images on social media increases, the Epilepsy Ireland Instagram page also moved past the 1,100. Epilepsy Ireland began work on developing a new website, which will be launched in autumn 2018 while the current site (epilepsy.ie) received 92,190 session in 2017 compared to 81,737 in 2016.

Sodium Valproate

The biggest advocacy issue of 2017 concerned the use and risks of the epilepsy drug sodium valproate (Epilim) in women of childbearing potential. Epilepsy Ireland and a number of other charities involved in the FACS (Foetal Anti Convulsant Syndrome) Forum continued to advocate for new measures to reduce the risks of children being affected by in-utero exposure to the drug and for better supports for families affected by FACS. Following the European Medicines Agency's (EMA) announcement of a new review into the 2014 valproate risk minimisation measures, we took part in the EMA's consultation process in April and participated in stakeholder meetings in the autumn. The issue received considerable media attention including on RTE's Prime Time and also significant political and policy attention. At the year end, discussions were ongoing with the Department of Health, HSE and Health Products Regulatory Authority and progress was being made on a number of key demands around safety, awareness and patient communication. A new ruling on the matter was expected from the EMA in early 2018.

Other advocacy issues

During 2017 Epilepsy Ireland continued to campaign for the expansion of the Free Travel Scheme to people with epilepsy who are not legally able to drive as a result of an epilepsy diagnosis and we presented a submission to the Minister For Disabilities, Finian McGrath in relation to this important issue.

Other advocacy issues during the year included proposed legislation and access to medicinal cannabis and the need for reasonable accommodations for students with epilepsy sitting state examinations, an issue that was outlined in an Irish Independent editorial by Epilepsy Ireland CEO Peter Murphy in June 2017.

Working with other organisations

Epilepsy Ireland is an active member of the following national and international organisations through which effective advocacy is conducted on behalf of people with epilepsy:

- International Bureau for Epilepsy
- The FACS Forum
- The Neurological Alliance of Ireland
- Disability Federation of Ireland
- The Medical Research Charities Group
- Epilepsy Ireland is also represented on the Clinical Advisory Group of the HSE's National Epilepsy Care Programme

Epilepsy Ireland CEO, Peter Murphy discussed sodium valproate on RTE's Prime Time.

TRAINING AND EDUCATION

Training For Success

Training For Success (TFS), Epilepsy Ireland's pre-employment training programme, remains the only course of its kind in Europe. First developed in 1998, it continues to provide a practical and inspirational experience for young people with epilepsy who, because of their condition, have experienced difficulties in progression of their educational and career aspirations.

In 2017 the programme, located in the Institute of Technology Sligo and funded by the Mayo, Sligo and Leitrim Education and Training Board, moved from FETAC Level 4 Certification to FETAC level 5 and in this move is aiming to become a full access programme for the students attending. TFS still continues its original remit of developing practical, interpersonal and communication skills to help develop the individual's personal confidence. We believe that the course and its upgraded syllabus will provide an even better solution for young adults' needs and expectations as we enter the Programme's 20th year in 2018. Preparations began in 2017 to introduce new modules such as Research and Study Skills, Maths, Communications and Word Processing. The outcome for the 2016/17 and 2017/18 academic years is that 15 students will have successfully completed the programme.

Health Professional Training

Since 2009, Epilepsy Ireland has been providing a training programme in Epilepsy Awareness and the Administration of Buccal Midazolam (BM) to health professionals and allied health professionals. The programme is the only one of its kind in Ireland and is delivered in accordance with the Joint Epilepsy Council guidelines on training standards for the administration of BM. 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 BM and receive instruction in the correct administration of BM.

2017 saw further growth in the demand and delivery of training days. 191 training sessions were delivered nationwide, compared with 152 in 2016; in total 1,863 people received the training in 2017 as compared with the previous year's 1,571, an increase of 26%. At the end of 2017, Epilepsy Ireland has delivered a total of 699 training days, providing this important training to 7,087 people.

Evaluation of the programme and in particular the extent to which participants' knowledge/ skills have improved or increased as a result of the course show an average of 98% strongly agree/ agree that the programme has improved their ability to deal with the emergency response involving the administration of BM for prolonged/ serial seizures. In 2017 we began to investigate opportunities for the extension of adapted training to pre-school staff, parents and family members. It is hoped that modified programmes will be available for delivery in 2018.

2017 Students of TFS include: Charlie Cosnett, Liam Caulfield, Chris O'Brien, Brian Faughnan and Kevin Regan.

TFS Course Manager, Honor Broderick, Pia Maxwell, Jenny Jimoh Omereye, Course Facilitator Maire Tansey, Michaela Murphy and Dr Marie McGloin.

Schools Education Programme

It was another typically busy year for the Schools Education Programme, which aims to raise awareness of epilepsy for those with the responsibility for ensuring a safe education environment. During 2017, 3,585 teachers, SNAs and students attended 154 Epilepsy Awareness presentations nationwide.

Epilepsy Awareness

Epilepsy Ireland, in keeping with our remit to provide information to people with epilepsy, family and carers which includes those in a professional capacity, also provided awareness presentations to a host of organisations during 2017. A total of 70 presentations were delivered nationwide in 2017 with 1,060 people in attendance. In 2017 a further 127 awareness/information events were also held, with 2,906 people in attendance.

In 2017, we also launched a new Employer's Guide to Epilepsy - the resource aims to assist employers' understanding of epilepsy and considerations relating to employment.

98%

of people surveyed agree that the Epilepsy Ireland training programme has improved their ability to deal with an emergency response involving the administration of BM for seizures.

Epilepsy Ireland Training Manager, Paul Sharkey giving a presentation in 'Epilepsy and Employment' at the 2017 National Conference in Sligo.

191

courses on the administration of emergency medication were delivered nationwide, compared with 152 in 2016

In 2017, 127 awareness / information events were held, with 2,906 people in attendance.

Fundraising Manager Michael Carty with the 2014 winner of The Rose of Tralee, Maria Walsh during a TY Expo in Punchestown to help promote Training For Success.

RESEARCH

The Epilepsy Ireland Research Funding Scheme was set up in 2009 to provide epilepsy researchers in Ireland with an avenue to access funding for quality, high-impact research. Since then, over €900,000 has been invested in 11 Irish-led projects. Four projects funded by Epilepsy Ireland were active in 2017, with three of these projects, all co-funded by Epilepsy Ireland and the Health Research Board (HRB). In 2018 we hope to pass the €1 million milestone.

At the launch of the SENSE Study: Prof. Agnes Higgins, Marcella Corcoran Kennedy TD and Peter Murphy, CEO, Epilepsy Ireland.

SENSE study

In February 2017, results from the SENSE study on the role and impact of Epilepsy Specialist Nurses (ESNs) in Ireland were launched by Minister Marcella Corcoran Kennedy. The three-year study was conducted by Professor Agnes Higgins and colleagues from Trinity College Dublin. It found that ESNs improved coordination and continuity of care; improved patient knowledge and satisfaction; reduced attendance at Emergency Departments; and improved access to services and communication between professionals, all while while remaining cost neutral. It concluded that the ESN service should be expanded nationally and that specialist ESN services should be provided in the areas of women's health, intellectual disability, mental health, older age groups and children/adolescents. The study continues to have a major role in ongoing advocacy efforts to develop and improve epilepsy services in Ireland.

Family Communication About Epilepsy

Dr Veronica Lambert and colleagues at Dublin City University also completed their study on parent-child dialogue about epilepsy and its associated stigma. A number of papers from the study were published including in the leading Epilepsy & Behaviour journal. The study also led to the creation of a new community of practice and a website (talkingaboutepilepsy.ie) with accessible information on the previous experiences of children with epilepsy and their parents talking about epilepsy.

Dr. Veronica Lambert, lead researcher on DCU research investigating family communication in epilepsy.

How2Tell

Dr Naomi Elliott's How2Tell Study at Trinity College Dublin on the issue of epilepsy disclosure was also completed in 2017. The purpose of the study was to design a set of educational tools to help adults with epilepsy learn about the best strategies to employ in telling others (family, friends, employers, work colleagues etc.) about their epilepsy. The experiences of almost 50 people with epilepsy were studied and a range of resources including a smartphone app, website, videos and printed resources were produced and published on epilepsy.ie. The resources are an important element of the support provided by Epilepsy Ireland's support team in addressing the often difficult issue of disclosure with service users.

How2tell

MicroRNAs and the Ketogenic Diet

Prof David Henshall's three-year study at RCSI entitled "MicroRNAs in the mechanism of ketogenic diet therapies and as biomarkers in paediatric epilepsy" continued throughout 2017 and will run for two more years. The research will investigate whether microRNA levels in blood samples or other body fluids (urine, saliva) can tell us which children with epilepsy will do best on the ketogenic diet. These studies will give doctors a new way to predict which children will do best on the diet and shed new light on how the diet works.

Prof David Henshall is investigating the role of MicroRNA in the ketogenic diet.

Can dogs predict seizures?

Also in 2017, a small grant was made to a project at Queens University Belfast examining whether untrained pet dogs have the ability to predict epileptic seizures and alert their owners. The object of the study is to assess reported claims that some family dogs display warning behaviours prior to impending epileptic seizures in their owners. The study also hopes to capture video evidence of such behaviours in dogs using a combination of voluntary home video recordings and 10 controlled single case study video recordings.

Epilepsy Ireland supported a study into whether dogs can predict seizures.

Epilepsy Deaths Register

Funding for the Epilepsy Deaths Register for Ireland, a partnership with UK charity SUDEP Action, University College Cork and Sheffield University, also continued in 2017. Launched in 2015, the Register aims to drive research and learn more about epilepsy deaths and how they might be prevented. (epilepsydeathsregister.org)

2017/2018 Research Funding Call

In October 2017, a new call for funding proposals was announced by Epilepsy Ireland inviting applications for research projects of up to a three-year duration to a maximum of €50,000 p.a. 15 applications were received and the evaluation process was underway by year-end. Proposals funded under this call will began in September 2018, subject to co-funding agreement with the HRB. In 2018 we hope to pass the €1 million milestone for our investment in research.

Other projects

We also collaborated in a number of other research initiatives including:

- The Epilepsy Partnership In Care (EPIC) project being conducted by the HSE's Epilepsy Clinical Care Programme and focusing on patient-centred care
- Promoting volunteer participation in epilepsy studies being undertaken at UCC, UCD and Liverpool University.
- Agreeing to formally collaborate on RCSI projects on sodium valproate risk minimisation and on the new Epilepsy Patient Portal (a web app which will give epilepsy patients access to interact with their electronic health record).
- A new DCU project promoting public involvement (PPI) in health research.
- The HSE/ E-health Ireland Epilepsy Lighthouse Project aiming to improve patient care through investment in technology solutions such as the Patient Portal and genomic sequencing.

The How2Tell Study is helping people with epilepsy in their decisions around epilepsy disclosure. Pictured is study Author Naomi Elliot.

FUNDRAISING

Fundraising to support our mission is an integral part of Epilepsy Ireland and the Irish public has continued to support our work in so many special ways. The generosity of those who undertake fundraising and donate to Epilepsy Ireland is crucial for the continuation of our services. Fundraising of any type, regardless of the number of people involved or amount raised, is appreciated by Epilepsy Ireland, as all funds raised allow us to continue offering services and programmes to people with epilepsy across Ireland.

Fundraising encompasses annual campaigns such as Rose appeals, the members' raffle, text-to-donate, the Women's Mini Marathon and Christmas campaign. It also includes national church-gate collections which continue to be an important source of funding. Individual donations, corporate support and event fundraising are also significant elements of the fundraising mix. In 2017, we began a collaboration with Permanent TSB who chose Epilepsy Ireland as one of their chosen charities for 2017/2018. Huge thanks must also go to Dublin Chamber who continued to support us in 2017.

Another important part of our fundraising is volunteer-led events such as National Saddle Up For Epilepsy, Tour de Gaggs and even sky dives! In the last year, there were hundreds of people who organised their own fundraising events, or participated in other Epilepsy Ireland events such as Ireland's Ancient East Peaks Challenge. Epilepsy Ireland was also thankful to Ireland Rugby Coach Joe Schmidt who continued his support by speaking at our fundraiser lunch in Fire Restaurant Dublin, which also included broadcaster, Kathryn Thomas. We want to send out our heartfelt thanks to all fundraising volunteers, donors and event participants who helped raise funds for Epilepsy Ireland in 2017. Some of their events are featured on this page. To see more, make sure to 'Like" Epilepsy Ireland on Facebook where we post great photos on a regular basis!

The need to raise funds is more important now than ever, in an environment of rising costs, static HSE funding and especially given the ambitions outlined our 2017-21 Strategic Plan. Any help or support you can provide Epilepsy Ireland is greatly appreciated.

Rick O Shea, Kathryn Thomas and Joe Schmidt, at the Inaugural Charity Lunch 2017 at Fire Restaurant, Dublin.

Niamh Keating from Kepak (right) presents Michael Carty, Epilepsy Ireland Fundraising Manager with a donation of €15,000. Also included in photo is Marianna Power (centre).

Ireland's Ancient East Peaks Challenge – Participants taking part in Epilepsy Ireland's Peaks Challenge in May 2017.

National Saddle Up for Epilepsy Organiser, Brenda Quigg with Fundraising Manager, Michael Carty after the 2017 event.

Andrew McCarthy, Group Mission Coordinator, Bon Secours presenting Epilepsy Ireland with a donation for the new Teachers Pack to Michael Carty. Also Included in photo, Niamh, Loretto and Judith from our Cork Office.

GOVERNANCE

Epilepsy Ireland is committed to achieving and maintaining the highest standards of governance and quality. In January 2015, the organisation was awarded the **Practical Quality Assurance System for Small Organisations** (PQASSO) Quality Mark Level 1. PQASSO is the leading quality assurance system developed for the non-profit sector. We have also implemented **Charities SORP** (Statement of Recommended Practice) in the preparation of our Financial Statements.

Epilepsy Ireland is committed to achieving the standards outlined in the **Statement of Guiding Principles for Fundraising**, and in 2017, the Statement was formally adopted by the Board. For more information, including our Public Compliance Statement and Donor Charter, see www.epilepsy.ie.

As at the 31st December 2017, Epilepsy Ireland was in the process of achieving full compliance with the Governance Code for community, voluntary and charitable organisations. This process was completed and confirmed by the Board of Directors in July 2018.

We confirm that our organisation complies with The Governance Code for the Community, Voluntary and Charitable Sector in Ireland.

Board of Directors

Epilepsy Ireland is governed by a Board of Directors who serve in a voluntary capacity. In 2017, the Board met on seven occasions.

Board of Director meetings

2017	Feb 20th	April 4th	May 29th	July 17th	Sept 5th	Oct 24th	Dec 4th
Mr. Mark Dowdall	✓	✓	✓	✓	✓	✓	✓
Ms. Cathy Grieve	✗	✗	✓	✓	✓	✗	✓
Mr. Michael McLoughlin	✓	✓	✓	✗	✓	✓	✓
Mr. Vincent Savino	✓	✓	✗	✗	✓	✓	✓
Mrs. Tessa Dagge	✓	✓	✓	✓	✗	✗	✗
Mr. Derry Gray	✗	✗	✗	✓	✓	✗	✗
Dr. Christine Linehan	✗	✓	✓	✓	✗	✓	✓
Ms. Carol Saarsteiner	✗	✓	✗	✗	✗	✓	✓
Mr. Tony Caravousanos	Not a member			✓	✓	✓	✗
Ms. Clare O'Dea				✓	✗	✓	✓

Dr. Michael Hennessy, Dr. Bryan Lynch, Dr. Brian McNamara, Dr. Joyce Senior, Dr. Brian Sweeney, Dr. David Webb and Prof. Norman Delanty did not attend board meetings in 2017.

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; strategic planning; financial procedures and controls; risk; and utilisation of reserves. In 2017, the sub-committee met on six 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.

Finance & Audit sub-committee meetings

2017	Mar 6th	May 16th	July 10th	Aug 29th	Oct 17th	Nov 27th
Mr. Michael Sheehy	✓	✓	✓	✓	✓	✓
Ms. Mark Dowdall	✓	✗	✗	✓	✓	✓
Mr. Michael McLoughlin	✓	✓	✓	✓	✓	✓
Mr. John O'Sullivan	✗	✓	✗	✗	✗	✗
Ms. Tessa Dagge	✗	✗	✓	✗	✓	✓
Mr. Tony Rhatigan	✓	✓	✓	✓	✓	✓
Mr. Paul Kehoe	New member				✓	✓

FINANCIAL REPORT 2017

In 2017, Epilepsy Ireland reported net outgoing resources of €274,119 (2016: net incoming resources €61,166). Net expenditure of €200,000 had been forecasted by the Board, driven by increased utilisation of strategic reserves for Epilepsy Nursing and Research funding and from other planned activities.

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.

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 2017)

	Restricted Funds 2017 €	**Unrestricted Funds 2017 €**	**Total Funds 2017 €**	Restricted Funds 2016 €	Unrestricted Funds 2016 €	Total Funds 2016 €
INCOME FROM:						
Donations and Legacies	**40,164**	**304,396**	**344,560**	-	484,080	484,080
Charitable Activities	**886,013**	**137,853**	**1,023,866**	912,730	128,951	1,041,681
Other Trading Activities	**57,435**	**234,543**	**291,978**	85,246	133,713	218,959
Investment Income	**0**	**2,207**	**2,207**	-	823	823
Other Income	**0**	**13,938**	**13.938**	-	18,732	18,732
Total	**983,612**	**692,937**	**1,676,549**	997,976	766,299	1,764,275
EXPENDITURE ON:						
Charitable activities	**953,227**	**463,263**	**1,416,490**	934,243	330,906	1,265,149
Raising funds	**23,089**	**303,453**	**326,542**	48,590	207,535	256,125
Other	**168,263**	**39,373**	**207,636**	156,185	15,156	171,341
Total	**1,144,579**	**806,089**	**1,950,668**	1,139,018	553,597	1,692,615
NET INCOME/(EXPENDITURE)	**(160,967)**	**(113,152)**	**(274,119)**	(141,042)	212,702	71,660
Unrealised gain on quoted investments	**0**	**0**	**0**	-	(10,494)	(10,494)
Taxation	**0**	**0**	**0**	-	-	-
Transfers between funds	**175,154**	**(175,154)**		155,753	(155,753)	-
	14,187	**(288,306)**	**(274,119)**	14,711	46,455	61,166
Total funds brought forward at 1 January 2017	**17,369**	**1,569,866**	**1,587,235**	2,658	1,523,411	1,526,069
Total funds carried forward at 31 December 2017	**31,556**	**1,281,560**	**1,313,116**	17,369	1,569,866	1,587,235

FINANCIAL REPORT 2017

Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Balance Sheet
As at 31 December 2017

	2017 €	2016 €
Fixed Assets		
Tangible assets	**145,211**	150,830
Financial assets	**0**	223,748
	145,211	374,578
Current Assets		
Stock	**6,424**	3,935
Debtors	**103,475**	42,977
Cash at bank and in hand	**1,413,218**	1,455,703
	1,523,118	1,502,615
Current Liabilities		
Creditors: Amounts falling due within one year	**(355,212)**	(289,958)
Net Current Assets	**1,167,905**	1,212,657
TOTAL NET ASSETS	**1,313,116**	1,587,235
FUNDS OF THE CHARITY:		
Restricted funds	**31,556**	17,369
Unrestricted Funds - General funds	**577,084**	700,826
- Designated funds	**704,476**	869,040
TOTAL FUNDS	**1,313,116**	1,587,235

OUR PEOPLE

Board of Directors

(as at 31 December 2017)
Mr Mark Dowdall (Chairman)
Mr Vincent Savino (Vice–Chairman)
Mr Michael McLoughlin (Treasurer)
Ms Cathy Grieve (Secretary)
Mr Tony Caravousanos
Mrs Tessa Dagge
Prof Norman Delanty
Mr Derry Gray
Dr Michael Hennessy
Dr Christine Linehan
Dr Bryan Lynch
Dr Brian McNamara
Ms Clare O'Dea
Ms Carol Saarsteiner
Dr Joyce Senior
Dr Brian Sweeney
Dr David Webb

Finance & Audit Committee

Mr Michael Sheehy (Chairman)
Mrs Tessa Dagge
Mr Mark Dowdall
Mr Paul Kehoe
Mr Tony Rhatigan
Mr Michael McLoughlin

Research Peer Review Board

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

Staff

(as at 31 December 2017)

Chief Executive
Peter Murphy

Services

Deputy CEO & Director of Services
Wendy Crampton

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)

Community Epilepsy Specialist Nurse
Sinead Murphy (Beaumont Hospital)
Yvonne Owen (Transition Nurse)

Fundraising & Administration

Fundraising & Communications Manager
Michael Carty

Communications Officer
Conor Culkin

Membership & Fundraising Officer
Ashley Butler

Churchgate Collections
Barbara Doyle

Fundraising Assistants
John Ryan
Judith Kelleher

Training & Communications Manager
Paul Sharkey

Training For Success Manager
Honor Broderick

Training For Success Facilitator
Maire Tansey

Finance Manager
Andrew O'Dwyer

Executive Assistant
Cathy Powell

Receptionists
Madge Geoghegan
Joan McDermott

OUR LOCATIONS

🟧 **Head Office**
249 Crumlin Road, Dublin 12.
Tel: 01 455 7500
Email: info@epilepsy.ie

Specialist Nurse and Transitional Nurse Helpline
Tel: 01 455 4133 Monday 9.30am - 1.30pm. Tel: 01 455 4133 Monday 2.00pm - 5.00pm

🟦 **North West**
Covering Donegal, Leitrim & Sligo.
Community Resource Officer:
Agnes Mooney.
Email: amooney @epilepsy.ie

Letterkenny Office
Grand Central Complex, Floor 2B, Canal Road, Letterkenny, Co. Donegal.
Tel: 074 9168725

Sligo Office
Model & Niland Arts Gallery, The Mall, Sligo.
Tel: 071 91 41858

🟩 **West**
Covering: Galway, Roscommon & Mayo.
Westside Resource Centre, Seamus Quirke Road, Westside, Galway.
Tel: 091 587 640
Community Resource Officer:
Edel Killarney
Email: ekillarney@epilepsy.ie

🟦 **Midwest**
Covering Limerick, Clare, Tipperary North.
Social Service Centre, Henry St., Limerick.
Tel: 061 313 773
Community Resource Officer:
Veronica Bon
Email: vbon@epilepsy.ie

■ **Kerry**
Covering Co.. Kerry
9/10 the Paddocks, Ballydowney, Killarney, Co. Kerry
Tel: 064 663 0301
Community Resource Officer:
Kathryn Foley
Email: kfoley@epilepsy.ie

🟥 **Cork**
83 Beech Road, Muskerry Estate, Ballincollig, Co. Cork
Tel: 021 427 4774
Community Resource Officers:
South Lee & West Cork:
Niamh Jones
North Lee & North Cork:
Loretta Kennedy
Email: lKennedy@epilepsy.ie
njones@epilepsy.ie

🟨 **South East**
Covering: Kilkenny, Wexford, Carlow, Waterford & Tipperary South.
C/o HSE, St. Joseph's, Waterford Road, Kilkenny.
Tel: 056 778 9904
Community Resource Officer:
Miriam Gray
Email: mgray@epilepsy.ie

🟪 **Midlands**
Covering Offaly, Longford, Laoish and Westmeath.
c/o The Charleville Centre, Church Ave, Tullamore, Co. Offaly.
Tel: 057 934 6790
Community Resource Officer:
Cliona Molloy
Email: cmolloy@epilepsy.ie

🟧 **East**
Covering: Dublin, Kildare & Wicklow.
249 Crumlin Road, Dublin 12.
Tel: 01 455 7500
Community Resource Officers:
Edel Curran, Carina Fitzgerald.
Epilepsy Ireland National Information Officer: Geraldine Dunne
Email: Geraldine: gdunne@epilepsy.ie
Edel: ecurran@epilepsy.ie
Carina: cfitzgerald@epilepsy.ie

■ **North East**
Covering: Louth, Meath, Monaghan & Cavan.
Unit 1a, Partnership Court, Park St, Dundalk, Co. Louth.
Tel: 042 933 7585
Community Resource Officer:
Mary Baker
Email: mbaker@epilepsy.ie

🟫 **Training For Success**
Manager: Honor Broderick
Institute of Technology Sligo, Ballinode, Sligo.
Tel: 071 915 5303
Email: broderick.honor@itsligo.ie

Online
Web:
epilepsy.ie
Facebook:
facebook.com/epilepsy.ie
Twitter:
@epilepsyireland
Youtube:
youtube/BrainwaveEpilepsy
Instagram: epilepsy_ireland

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epilepsy_ireland

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

Auditors
Deloitte
Chartered Accountants
Deloitte & Touche House
Earlsfort Terrace
Dublin 2

PQASSO
QUALITY MARK
LEVEL 1
NCVO

The Governance Code

epilepsy Ireland