

# Strategic Plan 2017-2021



*Shining a light on  
epilepsy since 1966*







# INTRODUCTION

Epilepsy Ireland celebrates our 50th birthday in 2016. This significant anniversary has allowed us to look back on the many positive changes for people with epilepsy that have happened in that time, not just in terms of treatments and health services, but also the contribution that Epilepsy Ireland has made to the lives of almost 40,000 people with epilepsy.

From early achievements like ensuring that epilepsy medications would be covered free of charge under what is now the Long Term Illness Scheme, through to more recent developments such as establishing our regional network, setting up the innovative Training For Success programme and the appointment of Community Epilepsy Nurses, the organisation has a proud track record of 'getting things done'.

Even in the term of our last Strategic Plan (2012-2016), a difficult time for the country generally and for the voluntary sector in particular, Epilepsy Ireland has developed and grown. Despite funding cuts and fundraising challenges, we have invested almost €1m in Irish epilepsy research, we have organised major annual awareness initiatives, and we have introduced a comprehensive set of new services including educational programmes for those newly diagnosed, self-management programmes and a greatly expanded training service. These and other developments have seen double-digit growth in demand for our core services in recent years.

In that same time, we have also seen significant improvements in epilepsy care in Ireland, thanks to the work of the National Epilepsy Care Programme and other initiatives. Internationally, epilepsy has been afforded greater priority in arenas such as the European Union and World Health Organization.

The last five years have not been without challenges however. We operate in an ever-changing health, policy, funding and regulatory environment. There are still many issues to be tackled, for example: the growing demand for community services; epilepsy and neurology services still lag behind those available in other European countries; there are significant gaps in how the rights of people with epilepsy and other disabilities are protected; and the battle against epilepsy stigma is not yet won.

It is against this backdrop that we present our 2017-2021 Strategic Plan. Developed over an 18-month period with input from a wide range of stakeholders, the Plan is reflective of both the environmental context and the needs and aspirations of our stakeholders, in particular people with epilepsy and their families who remain at the core of everything we do.

Over the next five years, we aim to protect and maintain existing services and activities, while also developing in new directions to ensure we continue to meet the needs of our service users and members. It's not just about what we do, but also how we do it and we are committed to maintaining a sustainable organisation operating under the highest standards of governance, organisational quality and financial management.

Our Plan is ambitious and many challenges lie ahead, particularly in resourcing our 21 objectives but with the support of existing and potential funders; our members, volunteers and fundraisers; the wider epilepsy community and the general public, we can continue to ensure that we achieve our mission and move closer to our vision of a society where no person's life is limited by epilepsy.

I want to thank everyone who gave input or feedback to the development of this Plan, whether through meetings, interviews, focus groups or surveys. Thank you also to the Strategic Planning sub-group of our voluntary board for guiding the process and to our staff and management team, particularly Wendy Crampton, Director of Services who has admirably led the process from the very beginning.

Please join with us as we now embark on our five year journey towards a brighter future for all those living with epilepsy in Ireland.

Peter Murphy

CEO

December 2016

# 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. About one in every 20 people will have a seizure at some time during their lives.

Epilepsy is one of the most common neurological conditions. In Ireland, 37,000 people over the age of five have epilepsy and there are an estimated 1600 - 2900 new diagnoses each year. Worldwide, more than 50 million people live with epilepsy. 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 and birth defects. Genetic mutations are also known to play a role in some cases. However, in about 60% of cases, no specific cause can currently be identified.

Epilepsy is a treatable condition and the majority of people can become seizure-free. However, Epilepsy Ireland estimates that

there are at least 10,000 people in Ireland living with uncontrolled seizures. For this group in particular, the consequences of an epilepsy diagnosis can be long-lasting and significant, often affecting the person's education, employment, psychological & 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. Epilepsy can also often cause significant psychological, social and economic consequences for 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).

The financial cost of epilepsy is also significant. In Europe, more than €15 billion is spent annually on the treatment of epilepsy, which equates to 0.2% of total GNP, and a figure comparable to that of lung and breast cancer combined.



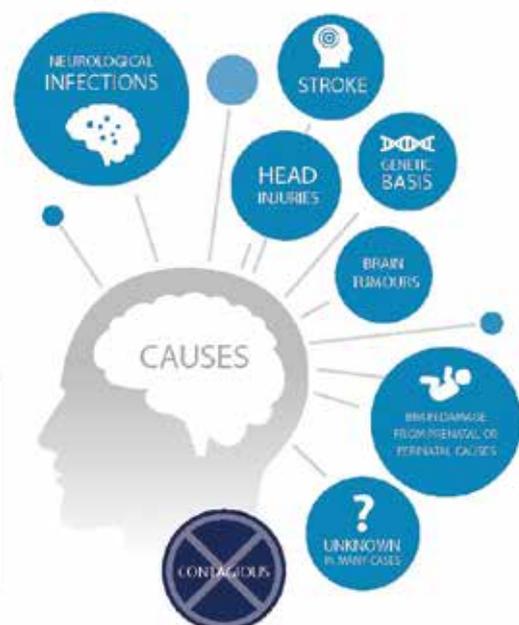
## WHAT IS epilepsy?

A NEUROLOGICAL CONDITION characterized by *recurrent seizures*

Seizures are due to *brief disturbances* in the *electrical functions* of the brain



Epilepsy affects people of all ages



# EPILEPSY IRELAND: A BRIEF HISTORY

1966

The Irish Epilepsy Association was founded. The driving force behind the setting up of the IEA was Professor Patrick (Paddy) McNally, a physician from Mercer's Hospital.

1968

The Association was successful in ensuring that the granting of free medications to people with epilepsy was included in legislation establishing the Long Term Illness Scheme (LTIS).

1976

The 8th International Symposium on Epilepsy came to Dublin in 1976 which attracted much national attention and helped lead to improved treatment and services for people with epilepsy.

1984

Despite turbulent financial times we managed to extend educational services throughout the 80s and today have 10 regional offices which provided crucial advice and support.

1997

EI hosted the 22nd International Epilepsy Congress in the RDS, one off the largest ever international events in Ireland at that time.

1998

The hugely successful Training for Success one-year pre-employment course was set up at IT Sligo for young adults with epilepsy. In it's 18 years, 85% of TFS graduates have found employment or continued in education after graduation.

After many years of campaigning Sinead Murphy was appointed as Epilepsy Ireland's first Community Specialist Nurse, a position she still holds today.

2002

2006

RTE 2FM Presenter Rick O'Shea answered the call to become EI patron.

The EI Research Funding Scheme was set up in 2009 to provide epilepsy researchers in Ireland with an avenue to access funding for important research aims. Almost €1m has been invested by EI to date.

Ireland Rugby Head Coach Joe Schmidt fronts a major seizure first aid awareness campaign for International Epilepsy Day.

2009

2015

**Future**  
Strategic Plan  
2017 – 2021

# ABOUT OUR WORK

Through our national and regional structures, we endeavour to work with and meet the needs of all those with an interest in the condition of epilepsy. This includes those who are members of our organisation and those who are not. It includes people living with epilepsy, parents of children with epilepsy and other family members. It also includes healthcare and other professionals, teachers, employers, community groups, service providers supporting people with epilepsy and the broader community. In all instances, the interests and needs of the individual with epilepsy is at the heart of what we do (see diagram 1). Our services for and work with each group is highlighted below in diagram 2.

Diagram 1: Who we work with

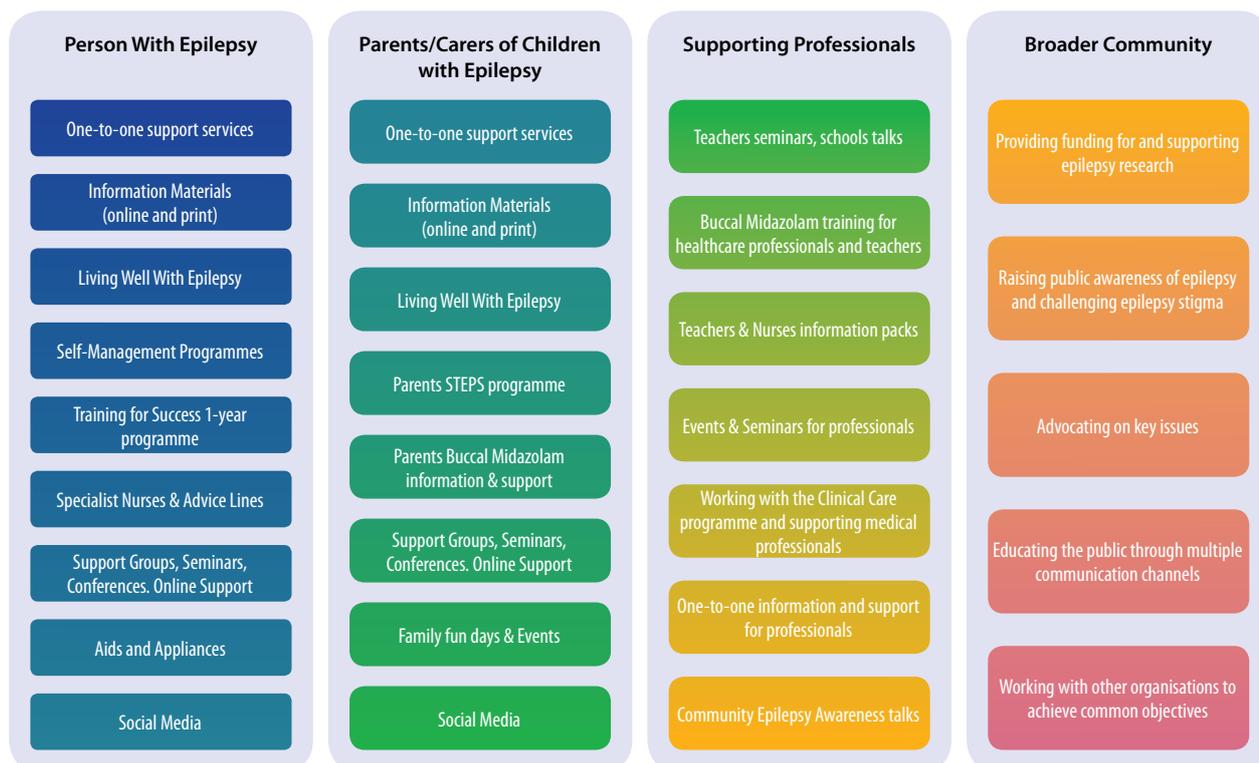
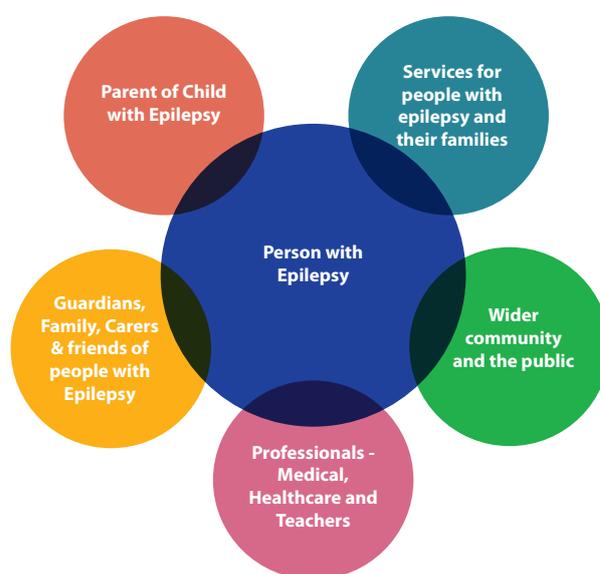


Diagram 2: Our Services & Activities

# DEVELOPING THE STRATEGIC PLAN 2017 – 2021

We have endeavoured to operate a fully consultative and transparent process in the development of this 5-year Plan. During 2015 and 2016, we conducted an extensive consultation process. We consulted with over 100 service users via an online survey and over 100 Epilepsy Ireland members participated in focus groups organised across the country. We consulted with leading medical, healthcare and research professionals working in epilepsy and undertook group discussions among staff, management and board. We believe that these consultations have shaped a Plan which captures and reflects the key concerns facing people with epilepsy in Ireland, their families and the wider epilepsy community.

## KEY THEMES

A number of key themes emerged from discussions with our stakeholders and these themes were critical in informing the direction and focus of the Plan. These themes included:

- The need to continue to advocate for the availability of neurological services for people with epilepsy.
- The continued need to provide timely and accurate information and support for adults with epilepsy and for parents of children with epilepsy.
- The need to consider groups with particular needs (people with epilepsy and an intellectual disability, those with mental health co-morbidities, older people, etc.).
- The need to engage and support younger people (teens and young adults with epilepsy).

- The need to ensure that people with epilepsy and their families are central to our work through their volunteering, participation in consultation groups, advocacy and fundraising.
- The need for capacity building, peer leadership and volunteering approaches to be developed for people with epilepsy

Many other themes also emerged and are contained within the Plan's 21 objectives, and the actions identified within them.

## NEW APPROACHES

An important feature of our Plan is the continuance and improvement of our existing range of services and activities. However, our Plan also identifies new ideas and approaches which we will endeavour to fund, develop and operate. See diagram 3.

## FUNDING

The implementation of the 2017 - 2021 Strategic Plan is dependent on funding being made available within each of the identified objectives. While this will entail challenges for the organisation, we will focus on securing the additional ongoing funding required to meet our objectives, while ensuring that our fundraising activities continue to develop in line with the needs of our strategy. Implementation plans and budgets will be agreed annually by the board based on the funding available.

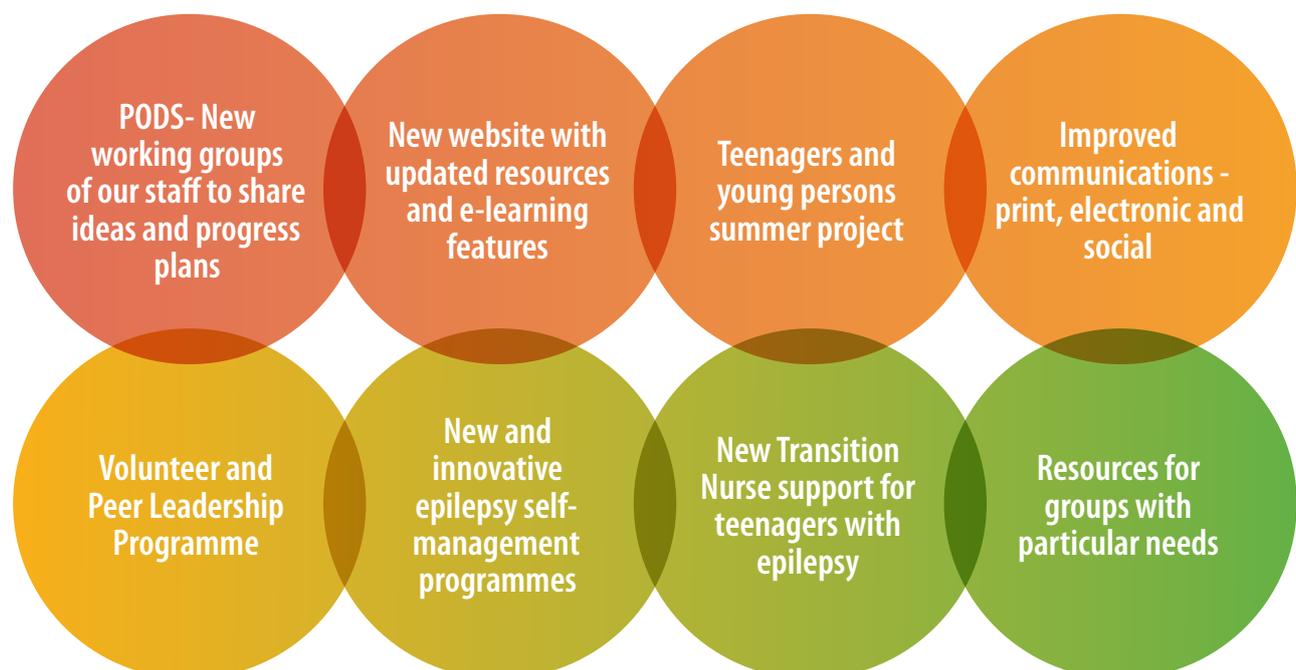


Diagram 3: New approaches

# EPILEPSY IRELAND 5-YEAR STRATEGIC PLAN: 2017 - 2021

## 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 to meeting the needs of everyone with epilepsy in Ireland, their families and carers.

## OUR SIX STRATEGIC AIMS

Epilepsy Ireland has identified six Strategic Aims which together form the framework for the Plan. These are: 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; and Operating a stable, transparent and accountable organisation meeting best practice standards. See Diagram 4.

Each of these Aims and their associated Outcome Statements are detailed below.



Diagram 4: Six Strategic Aims

Strategic Aim	Outcome Statement
Aim #1: To provide quality and relevant support, information & advice, meeting the needs of people with epilepsy, their families and carers, professionals and the wider community.	Outcome #1: People with epilepsy, their parents and families, and those with an interest in epilepsy are supported with, and are well informed about, the condition of epilepsy.
Aim #2: 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.	Outcome #2: Broader groups in society and the general public have a strong understanding of epilepsy – how it affects people and what it is, and how to respond to the condition appropriately.
Aim #3: To provide relevant training and education services to people with epilepsy, their families, and healthcare and other professionals.	Outcome #3: Groups and individuals with an interest in epilepsy improve their knowledge and skills through engaging with relevant training activities provided by the organisation.
Aim #4: 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.	Outcome #4: Epilepsy Ireland contributes to the body of research relating to epilepsy causes, cures and management and this research is effectively communicated to stakeholders.
Aim #5: To support people with epilepsy by raising the funds necessary to ensure the short-term funding requirements and long term sustainability of the organisation.	Outcome #5: The organisation is sustainable and continues to develop and deliver its services over the long term.
Aim #6: 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.	Outcome #6: The organisation demonstrates best practice in the areas of governance, quality, human resources and financial management.



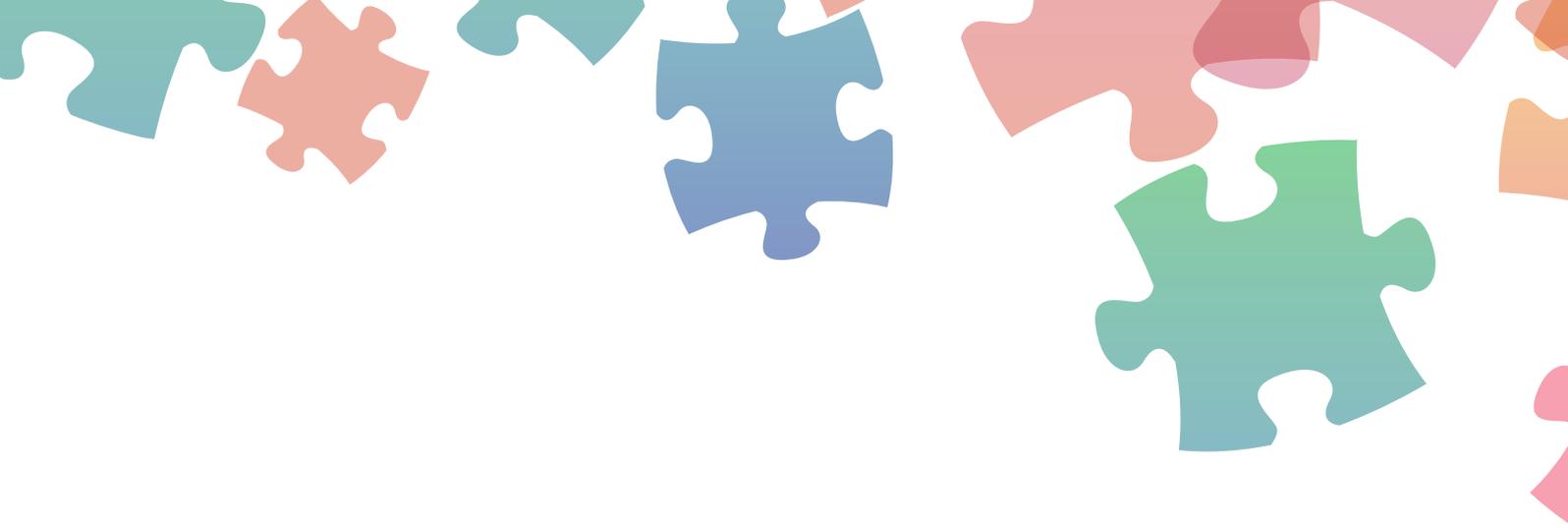
### OUR 21 STRATEGIC OBJECTIVES

Built into the six Strategic Aims are 21 Strategic Objectives that we will endeavour to meet during the five year period of the plan, subject to suitable funding streams becoming available and being maintained.

These 21 objectives will be measured using agreed Key Performance Indicators (KPIs) to ensure that we are reaching

and achieving the objectives over the five year period. Under Strategic Aim 6, we will introduce service audits, evaluation & measurement processes and feedback & monitoring mechanisms which will inform the measurement of the KPIs and allow us to monitor our progress against our objectives and our identified outcomes.

<b>Strategic Aim #1 : To provide quality and relevant support, information &amp; advice, meeting the needs of people with epilepsy, their families and carers, professionals and the wider community</b>	
<b>Strategic Outcome #1: People with epilepsy, their parents and families, and those with an interest in epilepsy are supported with, and are well informed about, the condition of epilepsy.</b>	
<b>Strategic Objective</b>	<b>Strategic Objective Outcome Statement</b>
Objective #1. Providing a high quality support and advice service for people with epilepsy, their families and carers	Outcome Statement: Epilepsy Ireland provides a high quality one-to-one support service and a range of up-to-date information resources to meet the needs of people with epilepsy, their families and carers, professionals and the wider community
Objective #2. Developing service user participation, involvement and peer-to-peer opportunities	Outcome Statement: Epilepsy Ireland will develop our service volunteering, peer support and will access service user expertise to ensure that service users are at the centre of everything we do.
Objective #3: Supporting service user needs for aids & appliances	Outcome Statement: Epilepsy Ireland provides aids & appliances to support people with epilepsy (ID bands and safety pillows) and provides up to date A&A information based on latest technology and developments.
Objective #4: Supporting children and young people with Epilepsy	Outcome Statement: Epilepsy Ireland will increase our work with children and young people through developing our services and resources for children, young people, schools and teachers.
Objective #5: Reaching particular groups with specific needs	Outcome Statement: Epilepsy Ireland will develop our approach, services and resources for groups with specific needs, including: Intellectual Disability, Mental Health, Older People and Complex Epilepsy. We will endeavour to provide adapted materials for those with particular needs.
Objective #6: Building relationships with professionals and shared working	Outcome Statement: Epilepsy Ireland will prioritise and support healthcare professionals working with people with epilepsy to provide maximum support and information exchange and build on our referral pathways.
Objective #7. Supporting Adult and Transitional Nursing Services	Outcome Statement: Epilepsy Ireland will develop a model of transitional care for young people with epilepsy moving from paediatric to adult services and will provide continued support to adult epilepsy medical services through our Adult Epilepsy Specialist Nurse.



**Strategic Aim #2: 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.**

Strategic Outcome #2: Broader groups in society and the general public have a strong understanding of epilepsy – how it affects people and what it is, and how to respond to the condition appropriately.

Strategic Objective	Strategic Objective Outcome Statement
Objective #8: Ensuring active and ongoing communication and awareness about epilepsy to key target audiences	Outcome Statement: Epilepsy Ireland will ensure that our communications and awareness-raising work is visible, effective and reflective of the priorities of the epilepsy community. We will ensure our activities are effectively tailored for our key target audiences.
Objective #9: Prioritising issues of risk, safety and SUDEP in our communications and across all areas of the organisation	Outcome Statement: Epilepsy Ireland will continue to prioritise awareness of SUDEP and other epilepsy loss through risk and safety education, supporting those who have lost a loved one, and maintaining SUDEP as an advocacy and awareness priority of the organisation.
Objective #10: Representing and advocating for the rights of those with epilepsy	Outcome Statement: Epilepsy Ireland will provide a strong voice to advocate on behalf of those with epilepsy and the epilepsy community and maintain a strong membership base to increase our impact at local and national levels.

**Strategic Aim #3: To provide relevant training and education services to people with epilepsy, their families, and healthcare and other professionals**

Strategic Outcome #3: Groups and individuals with an interest in epilepsy improve their knowledge and skills through engaging with relevant training activities provided by the organisation

Strategic Objective	Strategic Objective Outcome Statement
Objective #11: Providing quality training, education and self-management programmes to people with epilepsy & parents of children with epilepsy.	Outcome Statement: Epilepsy Ireland will continue to provide a range of quality training & education programmes to meet the needs of various groups including adults, young people and parents of children with epilepsy.
Objective #12: Providing Epilepsy Awareness & Buccal Midazolam training and information	Outcome Statement: Epilepsy Ireland will continue to provide and develop training in epilepsy awareness and the administration of Buccal Midazolam rescue medication to key groups including healthcare professionals and teachers.
Objective #13. Providing educational seminars, conferences and events	Outcome Statement: Epilepsy Ireland will continue to provide access to professional expertise through regular national and regional educational conferences, seminars and events addressing the needs of people with epilepsy and their families.
Objective #14. Developing website and online educational resources	Outcome Statement: Epilepsy Ireland will provide an improved online presence and service through a new epilepsy.ie and by developing new online resources and educational e-learning opportunities.



**Strategic Aim #4: 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**

Strategic Outcome #4: Epilepsy Ireland contributes to the body of research relating to epilepsy causes, cures and management and this research is effectively communicated to stakeholders.

Strategic Objective	Strategic Objective Outcome Statement
Objective #15. Providing research funding and supports to encourage and support Irish research	Outcome Statement: Epilepsy Ireland will continue to provide funding for epilepsy research in partnership with other funding organisations to support new and innovative research into epilepsy in Ireland.
Objective #16. Communicating research findings & volunteering opportunities and advocating for research	Outcome Statement: Epilepsy Ireland will develop our research communications to ensure that stakeholders are informed about research developments and opportunities to participate in research and we will continue to advocate for improved research infrastructure and expertise in Ireland.

**Strategic Aim #5: To support people with epilepsy by raising the funds necessary to ensure the short-term funding requirements and long term sustainability of the organisation**

Strategic Outcome #5: The organisation is sustainable and continues to develop and deliver its services over the long term

Strategic Objective	Strategic Objective Outcome Statement
Objective #17. Providing and developing the financial resources required to operate the organisation to its full potential	Outcome Statement: Epilepsy Ireland will review, manage and develop existing income streams; seek to diversify income streams and identify new sources of funding through grants, fundraising activities and corporate partnerships, while maintaining the highest standards of transparency and governance.
Objective #18. Managing and building relationships with key funders	Outcome Statement: Epilepsy Ireland will continue to maintain transparent and supportive relationships with our funders and meet all reporting and operative requirements.

**Strategic Aim #6: 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**

Strategic Outcome #6: The organisation demonstrates best practice in the areas of governance, quality, human resources and financial management.

Strategic Objective	Strategic Objective Outcome Statement
Objective #19: Operating good governance, financial management and managing organisational resources	Outcome Statement: Epilepsy Ireland will operate to the highest standards of governance and financial management, meeting the requirements of all relevant regulatory bodies and authorities, and will provide adequate IT, financial and technological resources to achieve the organisational aims.
Objective #20: Supporting people who are working or volunteering in the organisation	Outcome Statement: Epilepsy Ireland is committed to supporting our staff team and volunteers and to ensuring best practices are in place to support wellbeing, good communications, valuing peoples contributions and celebrating achievements.
Objective #21: Operating the organisation in line with recognised operating standards and ensuring that we provide a service which is informed by wider national and international models of working	Outcome Statement: Epilepsy Ireland will seek to ensure best practice and continuous improvement of quality in the organisation. We will work towards international quality standards and engage at national and international levels to continue to improve and reach high standards within the organisation.

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