



*Play your part for Epilepsy:
What will you do?*



@epilepsyireland



www.facebook.com/epilepsy.ie

Web: www.epilepsy.ie

Email: info@epilepsy.ie

Epilepsy

Epilepsy is one of the most common neurological conditions. It affects over 37,000 people in Ireland or almost 1% of the population. It can strike anyone, at any time in their lives and often without any obvious cause. Everyone with epilepsy shares one thing in common – that they have a tendency to have seizures. A seizure is a brief and temporary malfunction of normal brain activity and is often compared to a computer crashing. There are many different types of seizures, some of which involve the loss of consciousness and some which do not.

Epilepsy is very much a hidden disability. For many people, particularly those with uncontrolled seizures, living with epilepsy can be hugely challenging. It can significantly affect the person's education, employment, psychological & social functioning, self-esteem and independent living. Living with epilepsy also means learning to cope with the physical impact of seizures and the medications prescribed to control them. There is also an enduring social stigma associated with epilepsy that can be as problematic for many people as the seizures themselves. There are an estimated 130 epilepsy-related deaths in Ireland each year, about half of which are due to a poorly understood phenomenon called SUDEP (Sudden Unexpected Death in Epilepsy).



Epilepsy Ireland was established in 1966 to support and represent people with epilepsy and their families.

Our Vision

Our 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, their families and carers.

What we do

The work of Epilepsy Ireland is split into five priority areas:

Providing Information & Support

Through our network of support staff based in Dublin and in nine regional offices and via our Community Epilepsy Specialist Nurse, we are on hand to provide personalised support and advice for people with epilepsy and their families. Our regular events include support groups, community outreach clinics, hospital-based outreach, information seminars, workshops, conferences and family fun days. We also offer a range of aids and appliances including anti-smother pillows and epi-alert ID bracelets.

Raising Awareness of Epilepsy

One of the biggest challenges faced by people with epilepsy is the lack of public understanding of the condition. Epilepsy Ireland works to improve knowledge and reduce stigma through national awareness campaigns, by highlighting epilepsy in the media and by reaching out through workplaces, schools and other partners.

Training & Educating

Our Training For Success pre-employment training programme at the IT Sligo has been running since 1998 and is the only course of its kind in Europe. It provides a practical and inspirational experience for up to 14 young people with epilepsy each year that, because of their condition have experienced difficulties in their educational and career aspirations. We also provide epilepsy awareness and emergency medication training to schools, health-care professionals and the broader community and we run training days for healthcare professionals.

Advocating for people with epilepsy

We advocate in the political arena on behalf of people with epilepsy to promote legislative and civil rights and to eliminate all discriminatory practices regarding epilepsy. We represent the needs of people with epilepsy to government and policy makers, particularly in campaigning for better healthcare services. Epilepsy Ireland acts as an advocate for individuals in the areas of employment, law, education provisions and social welfare entitlements.

Funding Irish epilepsy research

Only by discovering more about epilepsy can better treatments be developed and maybe even one day a cure can be found. Through our Research Funding Scheme, we fund pioneering, internationally peer-reviewed research into key issues such as the genetics of epilepsy, the causes of SUDEP, service development and epilepsy stigma.



Recent Highlights...

- The *Living Well With Epilepsy* toolkit, an educational programme helping people recently diagnosed with epilepsy understand, record manage their condition.
- The *Be a TEAM player* national public awareness campaign fronted by Ireland Rugby head coach Joe Schmidt aimed at raising awareness of seizure first-aid.
- New Online Support Groups offering a forum for people with epilepsy to share their own experiences and meet others through a safe, confidential online application.
- Intensive campaigning efforts on key issues such as opening Ireland's two Epilepsy Monitoring Units and on generic substitution of epilepsy medications.

Targets for the near future...

- Establishing the Epilepsy Deaths Register for Ireland to improve understanding of SUDEP and drive research into its causes.
- Launch the STEPS (Support & Training in Epilepsy Self-management) programme assisting people to become their own epilepsy expert in an interactive group environment.
- Focusing on developing better epilepsy care for people with epilepsy and intellectual disabilities.
- Further develop successful programmes such as the ongoing Be Seizure Aware campaign and the Research Funding Scheme.

How can you help?

There are many different ways you can help Epilepsy Ireland achieve our mission. Here's our top 10 list of things you can do to help...

1. Represent Epilepsy Ireland

Sign up to take part in a run, walk or cycle in your area and get in touch for your sponsorship pack. Whether it's walking 10k in a mini-marathon or cycling from Cork to Donegal, you can raise sponsorship for Epilepsy Ireland by taking part.

2. Volunteer your time

Sometimes the old ways are the best! We're always keen to hear from people interested in volunteering for our collections, whether once a year or slightly more regularly. All you need is a few hours to spare! You can take part in our ongoing churchgate collections, Rose Appeals in February and October or help other occasional collections.

3. Organise an event

People do all sorts of things to raise money... from organising a coffee morning to cycling around the world! Some of the other great ideas we've come across include a sponsored car wash, a kids' Halloween disco, a tractor parade, a used book sale and an Oscars-themed party. Turn something you enjoy doing into a fundraiser!

4. Make a donation

If the old ways are often the best, then so too are the simple ways, and what could be simpler than making a one-off or a regular donation to Epilepsy Ireland. You can make a donation by phone, by post or online through our website or mycharity page.

5. Nominate us

Workplaces, schools, colleges and clubs do tremendous work every year raising money for charities. So if you come across a Charity of the Year initiative, let us know or nominate us! A small act on your behalf could lead to big results and also make big inroads in raising epilepsy awareness.



6. Join Epilepsy Ireland and stay in touch

Membership costs just €12.70 per annum. As well as all the benefits you'll enjoy as a member, it also ensures you are constantly in touch with us and you'll be aware of all the opportunities that come up to get involved and support our work.

7. Support Epilepsy Ireland fundraising

Whether it is an Epilepsy Ireland Brainteaser quiz night, our Annual raffle in Autumn, Christmas cards in December, calendars in January or even if you see a fundraiser at your local shopping centre, you can support our work by supporting our fundraising activities.

8. Once in a lifetime

Do you have a dream to bungee off a tall bridge, jump out of a plane at 10,000 feet or trek in South America? Whatever your dream, you can support your favourite charity and help realise it by signing up and collecting sponsorship. Contact us with your once in a lifetime dream!

9. Leave a Legacy

Leaving a legacy to Epilepsy Ireland in your will allows you to make a significant gift without affecting your finances today. Making your will provides a unique chance to provide for a charity that you care about and leave a lasting contribution. Contact us to find out more about leaving a legacy.

10. Bring others on board

We'll love you if you decide to get involved in our fundraising work, but we'll love you doubly if you bring a friend or a group of friends along for the ride! Make your fundraising a social occasion to really look forward to. At work, there's even more opportunities to get others involved - sell roses, Christmas cards, raffle tickets to colleagues or donate a prize/ voucher.

Me & My Fundraising



Laura Hall

Age 17, Co Wicklow

I was diagnosed with epilepsy when I was seven years old. It really affected my confidence. I was so nervous to do anything in case I had a seizure, but Epilepsy Ireland really helped me and my family in so many ways! A lot of people forget that it's tough on the family as well so for my mother, having Epilepsy Ireland there was so good for her, especially meeting all the other parents trying to deal with the same situations.

However without having epilepsy I wouldn't be who I am today. I want to be successful and prove that someone who has epilepsy can do just as much and be just as good as someone who doesn't.

Last year I went on Ryan Tubridy's radio show to raise awareness of epilepsy. Then I decided to run a horse show fundraiser for Epilepsy Ireland because I wanted to give something back and because I wanted to raise awareness among the people I've been competing with for years. I was delighted when my efforts raised over €2,000 for the great work that Epilepsy Ireland does and I want to encourage everyone to get involved in whatever way they can and give it a go themselves!

Volunteer or Donate



Please complete and return the form to:
Epilepsy Ireland, 249 Crumlin Road, Dublin 12
or contact us at 01 4557500 or fundraising@epilepsy.ie

Name Address
.....
..... Tel
Mobile Email

I would like to receive Epilepsy Ireland's e-newsletter (Clearly write your e-mail address in the space above)
The information above may be used by Epilepsy Ireland to advise you of other activities and initiatives which may be of interest to you. If you do not wish to receive such communication, please tick here

Volunteer...

If you or a family member or friend would like to volunteer at Epilepsy Ireland to help with our fundraising activities, please complete and return this form to us. We'll get in touch with you very soon.

I WOULD LIKE TO: Participate in Rose Appeals (February, October) Help with a Church gate collection
 Become a seller of tickets in the Epilepsy Ireland national raffle (Aug – Oct) Organise an event of my own
 I'm undecided and would like to discuss volunteering opportunities further.
The best time to contact me is: Morning Afternoon Evening

Donate...

ONE OFF DONATION: I would like to help continue the work of Epilepsy Ireland by making a donation
 €10 €20 €50 €100 My own amount €

PAYMENT METHOD: Credit/ Debit Card Cheque/ Postal order/ Bank Draft (payable to Epilepsy Ireland)
CARD PAYMENTS: I wish to pay by: Visa Mastercard Visa Debit and I authorise you to debit my account with the sum of € Name on Card
Card Number Expiry Date (mm/yy) CVV No
Signature

MONTHLY DONATION: Standing Order (Please return this to Epilepsy Ireland)
To the Bank Manager [Name of Bank]
Bank Branch Address
Name(s) of Account Holder(s)
Account No: Sort Code No:
Please pay to Epilepsy Ireland - Bank of Ireland, Walkinstown; A/C No. 88644504, Sort Code 90-02-87,
IBAN: IE63 BOFI90028788644504, BIC: BOFIE2D - the sum of:

€5 €10 €15 €21* Other €..... PER MONTH
Commencing on this date and monthly thereafter until further notice.
Signature Date

*A gift of €21 per month or €250 in a year may mean that Epilepsy Ireland can claim tax refunds worth up to an additional 72%!

What your support can achieve

€10 Could provide a special safety pillow to an Epilepsy Ireland member

€20 Could provide an Epi-Alert ID bracelet to an Epilepsy Ireland member

€50 Could provide a Living Well with Epilepsy toolkit and support session to a newly diagnosed person with epilepsy

€100 Could train a parent or special needs assistant in the administration of emergency rescue medication

€200 Could organise an outreach clinic for up to 7 locally-delivered one-to-one support sessions with our support staff

€500 Could pay for a family fun day out supporting children with epilepsy and their parents

€1,000 Could run an entire 6-week STEPS epilepsy self-management programme in one of 12 regional locations

€2,000 Could fund one of our ongoing epilepsy research projects for a month

€10,000 Could enable us to run the most important Epilepsy Ireland support and information event of the year, the National Epilepsy Conference.



How we raise and spend our funds

We are grateful for all funding we receive to enable us to meet our objectives and we are committed to providing a high level of accountability and transparency about how we raise and spend our funds.

In 2012, our turnover was €1.55m, of which €788,000 (51%) was in Section 39 grants from the Health Service Executive. This statutory funding is operated under nine regional service level agreements and we provide detailed annual reports to the HSE for each of these agreements.

We require additional funding from other sources in order to continue to provide our services and in 2012, €523,000 (34%) of our funding was from public fundraising activities that included donations, collections, corporate support, national campaigns, events and membership subscriptions. €145,000 (9%) was in grants from non-HSE sources and €77,000 (5%) was other income such as bank interest and training provided to health professionals.

Of every €1 we spent in 2012, 70c went to direct charitable objectives, 14c was spent on fundraising and 16c was spent on administration and governance. It is our belief that we extract maximum value, for people with epilepsy, from every Euro that we spend.

Epilepsy Ireland employs 24 people and the average salary paid is less than €34,500. No additional payments or bonuses of any kind are paid to employees. Our Board members and members of our sub-committees are volunteers who donate freely their time, skills and experience.

Epilepsy Ireland publishes audited accounts and an annual report each year, both of which can also be downloaded from www.epilepsy.ie.

For further details on our use of funds, see is.gd/useoffunds



Further Resources

All you need to know when planning or organizing your Epilepsy Ireland fundraising event: is.gd/frtips

Make an online donation: is.gd/donateEI

Submitting funds to Epilepsy Ireland: is.gd/submitfunds

Subscribe to our e-newsletter: is.gd/getEzine

Set up your mycharity sponsorship page: www.mycharity.ie



Get in touch

Talk to Ashley, Glenna, Noeleen or Peter at:

01 4557500

Email the team at:

fundraising@epilepsy.ie

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View our vids:

[youtube.com/BrainwaveEpilepsy](https://www.youtube.com/BrainwaveEpilepsy)



Epilepsy Ireland Head Office:

249 Crumlin Road, Dublin 12

CHY: 6170

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