



MEDIA VOLUNTEERING

About Media Volunteering

Media volunteers are vital to help us to increase awareness and understanding of epilepsy. While Epilepsy Ireland has designated spokespeople, often, when we receive requests, the media wants to hear from a person with a lived experience of epilepsy. By having a dedicated bank of media volunteers, we can approach people on our list about potential media appearances that we feel they would be comfortable with. Don't worry – agreeing to be a media volunteer doesn't mean you are an official spokesperson or that you are going to be contacted out of the blue by a member of the media!

Becoming a Media Volunteer

To become a Media Volunteer with Epilepsy Ireland, we need you to complete this form and send it back to our Communications team by emailing our Advocacy & Communications Manager Paddy at pmcgeoghegan@epilepsy.ie. Once we have reviewed it, we will add you to our list and keep in touch about volunteering opportunities when they arise and if appropriate to your situation / preferences. We'll also send you on a media volunteering guide with some tips for media appearances and sharing your story.

Personal Details (Fill in below)

- Name:
- Full Address:
- County:
- Mobile:
- Email:
- Date of Birth
- Occupation
- I am a person with epilepsy/ a parent of a person with epilepsy/family member of a person with epilepsy (**Delete as appropriate – if parent/family member, please state the person who are supporting and your relationship with them**)
- My preferred contact times are Morning/Afternoon/Evening/Any Time (**Delete as appropriate**)

Media Preferences

I am comfortable in discussing my journey with epilepsy on:

- TV (**YES/NO**)
- Radio (**YES/NO**)
- Newspapers/Magazines (**YES/NO**)
- Epilepsy Ireland social media channels & website (**YES/NO**)
- Local Radio (**YES/NO**)
- Local Newspaper (**YES/NO**)
- Podcasts (**YES/NO**)



Research requests

In recent years, Epilepsy Ireland have been increasingly approached by researchers seeking the input of people with epilepsy/their families as part of their projects/studies. Depending on the study, this might mean completing a questionnaire, taking part in a phone interview, donating a blood sample, sitting down with the research team itself, setting the questions a study should ask, giving feedback on the wording of participant materials, or advising on the practicalities of how a study should run. It is always entirely up to you which opportunities you respond to, and you will never be asked to participate in something that you do not want to. From time to time, we may approach our media volunteers on projects which they may be able to contribute to, and below you can record your preference on whether you would like to be approached about these projects.

I am interested in being approached about research projects which I may be able to potentially assist **(YES/NO)**

About You

If the media approaches us about doing a piece about the lived experience of epilepsy, it is important that we have some details about you and your journey with the condition to assess whether your story fits their request. Equally, having these details can be important to pitch your story to the media – please try and give as much information as possible. **(Add your answers below each question).**

- When was your first seizure?
- When were you first diagnosed?
- Do you know specifically what type of epilepsy you have?
^^If yes, please provide name and types of seizures you experience
- Are your seizures well controlled? *(If yes, how long – if not, how frequent are your seizures? If you have had a period of seizure freedom, and then had seizures return, please let us know this as well).*
- Do you feel you can manage your epilepsy well?
- How do you feel the diagnosis of epilepsy has affected your life?
^^Is there/has there been a particular period of your life where you have found managing your epilepsy particularly difficult?
- Are you comfortable telling others about your epilepsy? (Family, friends, colleagues)
- Do you feel the public has a good understating of epilepsy?
- Have you experienced any negativity or stigma because of your epilepsy?



- What has your experience been of epilepsy healthcare services in Ireland?
- If you were Minister for Health, what is one thing you would immediately introduce or change in relation to epilepsy health services in Ireland?
- Have you used any of Epilepsy Ireland's services for information or support about epilepsy?
^^What was your experience? If you haven't, please let us know if you would like to be linked in with your local Community Resource Officer.
- What would you say to someone who has been newly diagnosed?
- What did you wish you had known about epilepsy before you were first diagnosed?
^^If you could write a letter to you just after your diagnosis, what would you say?
- What do you feel is one of the most challenging aspects of living with epilepsy?
- What do you feel is the most important thing for the public to know about epilepsy?
- Is there anything you feel is particularly noteworthy about your journey with epilepsy?
^^Have you had surgeries, any interesting medical experiences, any particular challenges overcome?
- Is there anything else that you would like us to know about our journey and feel is important to share?

Data Protection

I understand that the information provided in this form will be shared with members of Epilepsy Ireland communications team to become a media volunteer. Epilepsy Ireland requires media volunteers to provide the public with a clear sense of what living with the condition is like which is why we require this data from you. I consent to this information being used for the sole purpose of becoming a media volunteer for Epilepsy Ireland. I understand that this may involve my details being passed on to members of the media for them to contact me directly and conduct a media interview (as indicated in your selection of media be it radio, online, TV or print). Prior notice shall be given to you before passing on these details on to members of the media. Please see our [Privacy Policy](#) for further details on how we process your information. Consent can be withdrawn at any point by contacting our Data protection officer on 014557500 or cpowell@epilepsy.ie.

NAME: **DATE:**