

International Golden Light Award Winner 2023

Wayne O'Reilly

IRELAND



My name is Wayne O'Reilly - I'm 30 and I'm from Wexford, Ireland. I've been living with epilepsy since February 2016. I'm incredibly proud to be put forward by Epilepsy Ireland (EI) for consideration for an International Golden Light award. I know each organisation can only put forward one nominee – and from my work with EI, I know just how many incredible volunteers and supporters that they have.

While there have been many ups and downs on my journey with epilepsy, from an early stage of dealing with this new part of life, I recognised the

importance of being open and honest about the realities of life with epilepsy.

While I was first connected with EI through their support services for people with epilepsy and their families, from hearing from others living with the condition, I knew that I could make a difference by not hiding my epilepsy and by getting further involved – both in terms of raising awareness and fundraising.

I don't think of my volunteering work as "work", nor do I really think about its impact. I put my hand up as I hope it can help others who are living with the condition or can help the public break down the misconceptions they may have about epilepsy. One thing I

passionately believe in is the need for members of the public to know the right things to do if they see someone having a seizure.

Epilepsy can strike at any time to anyone. I was 23 when I had my first seizure and never thought it would happen to me, but people should educate themselves on seizure first aid and be ready to help if needed. The best way I can help encourage them to do this is by being willing to help promote the message by sharing my own story with epilepsy.

As mentioned, I've had many ups and downs as part of my journey, culminating in a successful surgery in 2021. However, being in a good place now and in a period of seizure freedom does not mean I've forgotten about the early stages of my epilepsy journey, and when I was having regular seizures.

Living in the countryside at a young age, losing the ability to drive was a huge impact for me. At a time when I should have had more and more independence, I was reliant on family members and friends to get around. All the while, I was having seizures and the reaction from some was that they were extra cautious around you, making you feel like you were living with the plague.

Despite, this I've always tried to remain positive and promote to others what I always believed, even in the darkest days of my epilepsy journey - that there is a light at the end of the tunnel, and that with each passing day, that would lead to me understanding triggers and controlling seizures.

This is an important message for all those with epilepsy to know, and why I've been so willing to put myself out there. I believe my contribution which has had the most impact is being one of the faces of Epilepsy Ireland's 2022 International Epilepsy Day awareness campaign - I was the guy in the suit of armour in the ads and I loved everything about it.

I mentioned above how I felt people treated me differently due to my condition and the campaign was an exaggerated view of how the public can treat people with epilepsy differently due to the condition. I know it was very important to have "real" people living with the condition as the faces of the campaign, and when I was asked to be one of the faces, I didn't hesitate to say yes!

Seeing yourself on digital ads across some of the leading news and entertainment websites across Ireland and opening the Irish Independent (the biggest paper in Ireland) and seeing yourself in a suit of armour looking back at you is an experience! In terms of the impact of the campaign, I know that in total, it had 2.5 million impressions across social media, so I have no doubt that it made an impact in terms of increasing understanding epilepsy and seizure first aid across Ireland. I remain extremely proud to have played my part in this.

In conclusion, I am extremely honoured to be nominated for this award and would be speechless if I was a recipient. Regardless of outcome, my goal of increasing understanding of epilepsy will continue, as will my work with EI. My hand will always be up if asked to put my shoulder to the wheel to help increase understanding of epilepsy in Ireland and I hope this continued work is leading to brighter days ahead for future generations of people with epilepsy.