



Lorraine Lally

Ireland

Lorraine is a member of the bar of Ireland and is a practicing barrister with a particular interest in family law, immigration law, human rights law and other areas of civil litigation.

As a member of the Order of Malta Ambulance Corps in Ireland, she has treated seizures over the years as well as having them herself. Lorraine has a passion for youth work and advocacy.

She is involved in Advocacy campaigns for the National Women's Council of Ireland, Disability Federation of Ireland, the Neurological Alliance of Ireland and Epilepsy Ireland.

As a member of IBE's Global Youth Team, she enjoys working with members from all over the world



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I have had epilepsy since birth as a premature baby but I was diagnosed around 8 years old at a time when there was a hope I would grow out of it.

As a woman with a condition that for me has resulted in more stigma as a result of Catamenial Epilepsy.

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Catamenial epilepsy is a gender-specific type of epilepsy in which seizure frequency intensifies during certain phases of the menstrual cycle.

An increase in seizures in parallel with the menstrual cycle in some women with epilepsy has been noticed since ancient times.

Studies suggest that catamenial epilepsy is seen in 10 to 70% of women with epilepsy. Clearly, this range is rather big and is thought to be due to people using inconsistent definitions for catamenial epilepsy.



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The easiest way to explain it is to describe what it means for me in practice.

As a woman, we have a menstrual cycle and we bleed monthly. My grandmother celebrated the arrival of my monthly periods as a teenager. I was diagnosed with epilepsy as a child. There was no advanced education by the medical professionals or awareness of the links between the menstrual cycle and the seizures.

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As a person with epilepsy, you are instructed to keep a diary of your seizures. There was a clear link with mine my pre-menstrual seizures that would happen in my sleep which resulted in cracked ribs while also losing blood below the waist.

I know from speaking with women that I am not alone but the neurologists don't discuss the links and the pediatrician from a small rural hospital never told me about the possible connection.

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I found myself recently in a hospital bed with a nurse/midwife googling the type of epilepsy. She asked questions like whether was it the blood loss or the hormones that caused the seizures. I explained that I believe it to be the hormones.

There is now research on men of a certain age and the changes in their hormones and the impact on epilepsy. As a woman I let the medical profession put me in a box and I let the specialist doctors cover me with the stigma of not being able to share my lived experience.

I would now say that the stigma from doctors not working for the patients and listening is the greatest harm to any woman suffering as I did for two decades.

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I suffered for 20 years due to the stigma and not talking about my experience.

To all the men and women out there please use your voice to break the stigma.

Recently I got treatment from a female GP and a lovely male hospital consultant from Sudan who listened to me and heard my pain and suffering.

I am months seizure free now because I broke the stigma.



The last thing I need
is a spoon
when I'm having a seizure



There are as many myths about epilepsy as types of seizure.
When someone is having a seizure, don't put anything in their mouth.



International
Epilepsy Day
10th February 2020

Registered Charity Number: 20010553

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Please remember that you are not alone in the isolation that surrounds you. Trust in the evidence in front of you.

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International
Epilepsy Day



Discover more stories like Lorraine's and
learn about epilepsy stigma at
internationalepilepsyday.org

