

Chair, Deputies & Senators – first, thank you for the invitation to discuss this bill – a bill which is very much welcome in its aims to protect people in an ever more complex online environment.

Epilepsy Ireland is the national organisation representing and advocating for the needs of people with epilepsy and their families. We provide services and supports for those living with epilepsy and their families through our 11 Community Resource Officers and 9 regional offices across Ireland. Our vision is to achieve a society where no person's life is limited by epilepsy.

Epilepsy can be defined as the tendency to have repeated seizures in the brain. It is often described as an electrical storm in the brain. It is an extremely individual and often misunderstood condition. Each person's journey with epilepsy is different but generally speaking, almost 70% of those living with the condition will go on to become seizure free through the right combination of medication or treatment.

Photosensitive epilepsy is a reflex epilepsy in which sensitivity to flickering lights, such as strobes, some LEDs or other visual stimuli may provoke a seizure.

From the outset however, there are two key points that I want to stress:

- 1) Not all people with epilepsy are photosensitive – in fact, photosensitivity affects approximately 3-5% of all those living with epilepsy.
- 2) The issue which I am about to outline is one that as far as we are aware, has not maliciously presented in Ireland – yet.

Unfortunately, we have seen in other countries how a particularly disgusting form of online trolling of people with photosensitive epilepsy has become an issue.

This typically involves the deliberate targeting of people with photosensitive epilepsy with gif images or videos specifically designed to trigger a seizure in that person. For example, a child who set up a fundraising challenge event page in support of the work of a UK-based epilepsy charity was targeted with hundreds of flashing images.

We note that Head 49A of the General Scheme, in defining “online harmful content” takes an “enumerating” approach. Included is material which is a criminal offence to disseminate; cyberbullying material; and material promoting self-harm or eating disorders.

What does not appear to be included under the proposed definition is the dissemination of material which *is itself* designed to cause direct harm – a prime example being flashing videos designed and intended to cause seizures in a person with photosensitive epilepsy.

It may or may not be the case that such materials are already illegal under existing laws, but we believe that provision in the legislation can and should be made to add greater clarity and protection for those who could be seriously harmed.

The impact of these kind of attacks cannot be underestimated.

I would stress to the members of committee that seizures can be life-threatening and to target a person in such a way is a truly heinous act.

We believe the definition of “online harmful content” needs to be expanded to protect people with photosensitive epilepsy in Ireland when they go online. We hope you agree that this is a modest ask and that our ask fits within the ethos of what this legislation is trying to achieve.

Let us make sure that targeted, malicious attacks like the example I mentioned earlier will not be tolerated and that perpetrators will be criminally liable if they engage in such behaviour.

Thank you for the opportunity to put forward this key point.