



**Edna Milena  
Segura Rubio**

Colombia

Edna Milena Segura Rubio is the director of Comunidad Familias Púrpura in Colombia and has had epilepsy since childhood.



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I have had epilepsy since I was 8 years old and have had many struggles with this disease. Stigmas such as the fear of being rejected or the shame of having a seizure or the fear of people, or the fear of people thinking that the disease was contagious made it more difficult to deal with these circumstances as I didn't have the knowledge about epilepsy.

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The same thing happened when I went through primary and secondary school because the teasing, the foul language, and being rejected in academic activities made it even more frustrating.

However, I was fortunate to meet and have friends who protected, accompanied, and defended me. They didn't quite understand what was happening to me, but they were there.

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When I started researching and studying epilepsy it helped me to feel better.

Meeting others like me and learning key terminology to be able to explain what was happening to me, substantially changed the way I thought and acted about it.

People may still be afraid, but you have the tools to start teaching them.

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After completing my university studies in Social Work and after leaving in search of a job with the intention of giving my best and applying the knowledge I had learned, I came up against a wall of ignorance and indifference.

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Lack of knowledge on the part of educational institutions, the labour sector and society in general are the real barriers to the inclusion and acceptance of people with epilepsy, greatly affecting their physical and emotional health, and limiting their opportunities to lead a normal life.

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Misconceptions about the medical condition still persist. For example, believing and asserting that it is a mental disorder and retaining terms such as epileptic or lunatic or that symptoms are referred to as "seizures".

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These terms are being re-evaluated and changed to *neurological disease*, *neurological disorder*, or *neurodevelopmental disorder*, radically transforming the conception and management of the disease.

Its dissemination and establishment in the common language allow for a less aggressive, kinder, and more comprehensible knowledge in dealing with people and families with this medical condition.

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It is our responsibility to take actions that impact and reach out to the hearts of other epilepsy patients and families, as well as all people around the world.

Personally, having epilepsy has led me to find my purpose in life and has paid off in helping others by mitigating some barriers within the epilepsy population and beyond.

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The creation of the Purple Families support network and the social organization Comunidad Familias Púrpura together with other patients and families has been a very special process.

To interact with different patient organisations, carrying out activities to raise awareness and education activities, getting to know and share spaces with different medical organisations, and learning directly from specialists has been very enriching.

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I am grateful to all the people who have accompanied and supported me unconditionally and to the families who are part of our community and who encourage and push me every day to continue working to change our reality.

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Education and changing perceptions of epilepsy can radically change our world, giving us more strength to move forward, and empowering us to deal with any situation and lead a full life free of prejudice.

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Discover more stories like Edna's and  
learn about epilepsy stigma at  
[internationalepilepsyday.org](http://internationalepilepsyday.org)

