



Scarlett Paige is the chair of IBE's Global Youth Team.

Scarlett Paige

Australia



Scarlett was diagnosed with epilepsy at the age of 19, but little did her family know that her epilepsy journey started long before this.

At the age of 5 months old, whilst being held in her Mother's arms, Scarlett had 2 generalised tonic-clonic seizures.

When taken to the emergency department her parents were told not to worry as they were febrile seizure. Her parents were sceptical of this as Scarlett didn't have a fever at the time.





During my school years, I found it very difficult with reading and writing this was due to what we now know as Palinopsia.

Palinopsia is an epileptic phenomenon - the preservation or recurrence of images in the visual field after the removal of the real stimulus - which left me seeing multiple words and numbers over and over again.

This didn't just stop on paper, I could see multiple objects, including people. I always knew which was real as the afterimage was in light blue or grey.

Not knowing that others couldn't see this also I didn't mention it, thinking it was normal.



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In 2006 at the age of 18, I woke to what I call a complex world.

Standing in the supermarket with my Mother a complex focal impaired seizure came from nowhere.

Six months of them becoming increasingly worse, with yet more missed diagnoses and three generalised tonic–clonic seizures.

The local hospital decided to look more closely at what might be causing them.

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It was only by a chance meeting with Professor Mark Cook that he put a name to what was happening and this name was epilepsy, a name I hate to love.

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The number of friends I lost due to not being able to drive or go out late and needing to take time out to rest. Not to mention losing my first job in a career I studied so hard to work in, this was one of the hardest times I've been through.

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The amount of shame that comes from living with epilepsy is only brought on by stigma from the wider public.

This stigma comes from ignorance.

If there's one thing epilepsy has taught me it's how to be strong, stand tall and speak up for those who can't be heard.

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I have made it my mission to help break the stigma, by telling my story and not being afraid of what reaction I may get.... I have had them all by now.

The friends and new ‘family members’ I have met along my journey, sure have taught me there is strength in numbers and that’s what we need to stop the stigma.

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

