



BC Epilepsy Society

A Personal Story About Epilepsy

Presented on March 26, 2013
at the Park Inn Hotel and Suites
in Vancouver, BC.

Below is a biography and a speech about and from one of the speakers at the *All About Epilepsy* event organized by the BC Epilepsy Society. Reproduction of this is not permitted without permission from the authors. Contact that BC Epilepsy Society at 604-875-6704 or at outreach@bcepilepsy.com if you have questions or require more information.

Speaker Biography

Analisa is 27 years old and she was 8 years old when she was diagnosed with epilepsy. She was born with a mild case of cerebral palsy so she was already at a higher risk of developing epilepsy. She has multiple types of seizures. She describes her seizures as making her stare into space or making her fall and shake. To help stop her seizures she has had two brain surgeries and her mom estimates that she has been on over 25 different medications. Unfortunately, she still has frequent seizures. Even though she lives with these challenges she is an active member with volunteering in her community, particularly with epilepsy awareness workshops and presentations. Analisa has participated in workshops that the BC Epilepsy Society has done for medical students. She is also currently a spokesperson for an epilepsy awareness program called E-Action from UCB. This program organizes, trains, and funds people with epilepsy to travel throughout the country to speak about their experiences with epilepsy.

Analisa's Speech

As you all know my name is Analisa and I have epilepsy. Now as anyone knows, epilepsy is sort of like that one relative you have that you have that no one likes and you constantly make excuses as to why they can't come visit because when they do they take over your home and disrupt your life. They can be extremely hard to get rid of and worst of all they show up when you least expect it. Epilepsy has wreaked havoc with my life for 18 years now, but with the support of my family and a sense of humor I have been able to get up everyday and enjoy my life.

Unfortunately at this point my seizures are not under control which means every time I step out the door I wonder if today is the day I fall and if I do will they stare, will they point, will they break into the Harlem Shuffle because they think I am dancing or will they just step over me and keep walking which they commonly do. I do believe if the public was more aware and educated about the disorder the stigma associated with epilepsy would allow many of us to walk a little taller and walk without fear.

Epilepsy has made it difficult for me to take part in school, which presents a problem because I have problems with my short term memory further education has at this point been put on the shelf. Joining a school sports team was also difficult. In grade 6 I joined the girls basketball team but it was short lived because every time the ball was shot my way I had a seizure. In the end I was benched for my own safety. Friendship can often be difficult. If I am having bad seizures and I go out people often feel they are being my caregiver, rather than just enjoying themselves. My life has not gone the exact way I expected. Most people my age have finished their degree or have a career. For me I am still waiting at the starting line.

While most people my age have left the nest, I am still at home. Then again there are a lot of people moving back home, so at least I saved in moving costs.

There are nights when epilepsy decides to take my brain on a wild ride. When every time I shut my eyes I have a seizure and end up taking ativan to stop them. That means not only do I miss out on a good nights sleep but, the next day I'm exhausted. This makes it hard to find a job, do a job, and keep a job as employers need you to be on time and stay focused.

In spite of all the negatives, I have found a way to live in a world with epilepsy. I may not play sports but I still train and ride my bike and I swim with a buddy. I may not hold a conventional job, but I can volunteer and still be a contributing member of society. I have learned that times and people change. That living at home with a support system can come in handy, especially on laundry day.

But most of all I have learned that although I may dance to a different drummer I am still dancing. That you can't define epilepsy in one way nor can you let it define you. We are all different, but epilepsy is still a debilitating disorder. That for everyone of us who comes out into the light, there are still more hiding in the dark because the ignorance and stigma associated with this disorder.

It is my hope and dream that if I can reach one person and help them turn on a light then all my challenges will have been worth it. After all we should not allow epilepsy to define us, that is up to us.