

I am Lee May Yoong, born on the 3rd of September, 1991. At the age of 3 years old, I was diagnosed with epilepsy and my seizures stopped when I was 12 years old. According to my mother, my seizure normally will occur when I have flu symptoms and high fever but there were two incidents on different occasions that I had seizure without fever. She used to sponge me regularly to lower my temperature and I had to watch after what I eat. During my younger days I was not allowed to go on adventurous rides, swim or involved in active games.

I studied in SRJK(C) Tsun Jin from 1998 to 2003, SMK (P) Pudu from 2004 to 2008 and completed my education at SMK (P) Puterijaya from 2009 to 2010. I managed to sail through mainstream government school and completed my secondary school with average results.

During my school days, my classmates were very helpful but I was seldom invited for social activities because of my epilepsy/health.

I am thankful and happy that I have a very supportive family members who have always been there to support me, cheer for me and celebrated all my achievements with me.

Unfortunately, in year 2007 I was diagnosed with suprasellar germinoma (a type of brain tumour). I underwent Chemotherapy & Radiotherapy treatment, and I was fortunate enough that the tumour disappeared. However, the whole tumour experience had caused complications in which my movement are slower and my memory is affected to some extend.

I am happy and blessed because somehow I managed to pass all my school exams despite the struggles I had to go through, living with epilepsy and also being diagnosed with suprasellar germinoma.

I have constantly been attending epilepsy programmes and activities organised by the Malaysian Society for Epilepsy (PEM) since I was in primary school. I helped the society in many of their events including giving talks, distributing pamphlets to the public and sharing my story on epilepsy to others during their support group meetings.

In 2013, PEM together with Spastic Children's Association of Selangor & Federal Territory organized an Annual Charity Walk/Jog/Wheel-A-Thon to raise fund for the disabled. I participated in the walkathon to raise funds for PEM and to promote epilepsy awareness to others. I have regularly been participating in charity walks, along with my parents and PEM members, to help collect donations for the society and to inspire others living with epilepsy to lead an active and healthy lifestyle.

In November 2014, I became a member of United Voice (UV) from the advice of a friend, Karen. I attended SST class whereby I learned self-motivation, self-expression, and self-advocacy. I learned to be more confident and encouraged to speak up during the meetings.

I was once invited to the Disability Equality Training (DET) to share my knowledge and experience on people with learning disabilities to a group of employees from one of the biggest budget airway companies in Malaysia called Air Asia. I was also invited to participate in the ASEAN Summit 2015. The theme that year was "Our People, Our Community, Our Vision".

I was happy and honoured that I have been chosen to participate in the 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) that was held at Melbourne, Australia, from 14-19 August 2016. I shared about my learning experience from a PhD research project that participated in. I was selected to be part of the committee as the Treasurer for two terms from 2018 – 2021.

Through Self-Advocacy I have learned self-determination, how to speak up, make my own decisions, know my rights as a citizen, and know my responsibilities. I manage to improve my skills in problem solving, be independent, yet knowing when to reach out to others when I need help. I value friendship and family very much.

I hope to see more people joining the epilepsy support group in Malaysia because they can learn to be more independent and build their own support system. Each of us goes through life with different challenges. I have mine but I am adamant to make a positive change to my society, fight stigma and continue to raise awareness for people with epilepsy.