

IBE Golden Opportunity Award

Candidate: Lai Siew Tim

“There is no greater agony than bearing an untold story inside you”. – Maya Angelou

This quote triggered a memory from my twenties. During a counseling session where I asked her how *she* was doing, *she* responded, “I am doing fine.” “Really?” I asked. It was not being; I was genuinely asking. Her silence spoke volumes as *she* placed her shaking fingers to her mouth to cover an involuntary cry.

Moments later, *she* told me about the stress and anxiety *she* was going through between school, work, and family. “When my seizures got bad, they would hospitalize me and change or add meds,” *she* said. “When my meds are changed, there would be a honeymoon period until my brain figure out how to work around the new prescriptions, and the seizures would start again. When is this going to end?”

Just imagine someone like her coming to you for assistance. They are emotionally paralyzed by events in their life. They focus on their pain and grief. Their despair is so acute that it pervades their entire life. Their relationship is breaking down and heading towards a divorce. They can’t focus on work and are getting in trouble with their boss. They are caught in a cycle of destruction and pain – revolving around the identity of being an ‘*epileptic*’ patient.

I have had the privilege to listen to their experience as a person living with epilepsy during my appointment as a mindfulness-based therapist under the Epilepsy Research Programme at the University Malaya Medical Center, Malaysia. During the process of history taking, I utilized psychotherapeutic techniques and assessments to understand the needs of people with epilepsy (PWE). This allowed me to provide individualized intervention for PWE to relate to their diagnosis and learn to cope with stressful life events. After conducting over 60 sessions of group therapy with caregivers and those affected with epilepsy, I realized that the narratives shared in a session – positive or negative; the weightage it carries revealed an opportunity to look at the chapter one is currently writing, have written in the past, or plan to write for the future. From my engagements with these individuals, I wondered: “*how can their stories be remembered, shared, and made known to others?*”

Research became my platform to share and advocate for PWE. I began my doctoral degree in 2016 and got involved in a couple of research projects related to topics raised in the International Bureau for Epilepsy (IBE) research task force. My responsibility included conceptualizing the study design, collecting data, and manuscript writing. I managed to represent my field of interest (i.e., positive psychology, mindfulness) to raise public awareness, as well as policymakers, of the research conducted through my subfield. My passion for research carved the opportunity to present my findings at various ILAE congresses. I received an award for the ILAE Young Leadership Development program, and subsequently joined the Young Epilepsy Section, where early stages of my research aspiration were met.

Aside from clinical research, I was appointed as the secretary of the Malaysian Society of Epilepsy (Persatuan Epilepsi Malaysia, PEM), which is a member of the IBE. As the secretary, I engage with the public, social workers, patients, and caregivers who have questions or concerns regarding epilepsy. I have contacted different speakers for educational talks and planned the outline for the monthly support group meetings. Our culminated effort resulted in an increase of respondents joining the society membership by 70% within 8-months.

PEM's goal is to improve the quality of life of PWE and with one of our mission pledges towards building funds, we are aiming to expand our organizational structure. Amid the COVID-19 pandemic, coupled with higher donor expectations, increased regulation and cuts to traditional funding streams, charity fundraising has been challenging. As a member of the organizing committee, I believe there is much more that we can and should be doing to better reflect the communities we serve.

Today, more than 50 million people are living with epilepsy. This illness has been stigmatized, as people are misinformed or uninformed of the condition. Some of them think there is only one type of seizure, the tonic-clonic or grand mal. Some think that all people with epilepsy are crazy, disabled and that their children would be sick. What could be done to improve their life?

The encounter with a person with epilepsy has influenced my outlook and allowed me to reflect deeply on the various key roles (i.e. researcher, academician, and PEM secretary) I now handle. Should the International Golden Light Award provide me a platform, I hope my voice would echo the feelings and sentiments of the community I currently serve, and make it known that we are all here; that all our struggles, efforts, and passions, heard though we are not seen.

(796 words)