

Reflection

Chu Ching Yuen

After joining the 3-day International TSC Conference in Toronto, I was enlightened with knowledge and filled with hope. As I knew before, TSC is a sad disease. The patients have benign tumours that grow around the body. In the brain, 90% of them have seizures and poor brain development. In the kidneys, Around 50% of them have big tumours (called AML) that can bleed and hinder their kidneys from working. Some died of lung tumours, while others keep fighting for government subsidies on their drugs.

Although I have been working on the prevalence data of TSC in Hong Kong, in the hope to fight for better resource distribution to these patients, I used to think that it is tough. They are the group "to-be-sacrificed", because the amount spent would be considerable, but the number of them to benefit is small. I knew these patients suffer a lot, but I also understood the difficulties to convince HA to fund them. As well as to fund rare disease research in general.

However, the Conference inspired me to think otherwise. In the plenary sessions, various professors talked about their research regarding various aspects of TSC, ranging from molecular diagnosis to clinical practice targeting TSC-associated neuropsychiatric disorders. The findings were amazing, and the speakers were passionate too. It was exciting to think about the fact that the gene causing TSC was found not more than 30 years ago, yet there have been a great leap in the understanding of various mechanism causing the various symptoms of the disease. Many of these researches, which primary aim was on TSC, could benefit the understanding of other diseases too. The Conference experience enriched my knowledge on the research of TSC, and also convinced me that the future of TSC research is bright, and TSC patients could have their diagnosis and management improved substantially.

Meanwhile, I was also delighted to learn that there are increasing collaboration between different countries. On this rare disease with multifactorial problems, it is essential to expand the size of study population in the research, as well as to share experience among patients and practitioners in different countries. On a working group discussion, talking about the expansion of clinical trial to involve patients in different countries, my fellowship students and I shared about our experience in translating international guidelines and questionnaires for local TSC. This provokes further discussions. Some of them also came to our poster presentation later that day, listened and gave more advice to us. What touched me was that the experts were really friendly and humble, and they were open to new ideas in the Conference. They served as role models to me, and encouraged me to be a lifelong learner.

Furthermore, it was the first time I gave a poster presentation. It was a new lesson to me, in terms of designing the poster, selecting the important information to present, give respond to the questions regarding the methodology. This experience equipped me with better presentation skills. It also made me reflect on the limitation of our study, and gave me ideas about what we could further work on to make a more comprehensive patient registry.

Last but not least, we present what we have learnt to TSC Association of Hong Kong (TSCAHK). The patients and their carers had been eager to learn about the treatment of TSC, and this time, they were equally eager to learn about the research development presented by me and my team. We selected the essential and easy-to-understand points to share with them. From the questions asked by the patient carers, I also learn about what they really care about. More importantly, I was impressed by the perseverance of patient carers in searching for the best care to their patients. I was humbled by the patient carers, because I found that what I could do was very little. They were the ones who never give up, who were always eager about understanding the disease.

TSCAHK gave me a thank-you card after the sharing, and it said:

"Where there is hope, there is faith.
Where there is faith, miracles happen."

In the world that is full of troubles, the TSC experts and the patient carers showed me the power of faith and hope with their actions. The whole Conference and sharing experience built and strengthened my belief: our society should never give up these rare disease patients. They should be taken care equitably. Though the resources are limited, with hope and faith, we would walk alongside with the patients and their carers - help them with knowledge, and share their journeys with empathy.

