

JANUARY 2023 ISSUE

EPILEPSY LINK

A NEWSLETTER OF THE EPILEPSY COMMUNITY



Thank You

for joining us at

ECG 27th Annual General Meeting

WHO'S WHO IN THE NEW EXCO? (2022 TO 2023)

President:

Dr Choong Chew Thye

Vice-President:

Diana Koh

Honorary Secretary:

Goh Keng Hwee

Assistant Secretary:

Ang Wei Jie

Welfare Officer:

Goi Ming Ying

Honorary Treasurer:

David Tan

Assistant Treasurer:

Calvin Koh

Council Members:

- Hayden Tan
- Calvin Zhong
- Dr Leong Wei Shin
- Patrick Soh
- June Chong

Congratulations to all elected members of the 28th Executive Council! We are heartened that more individuals are coming forward to contribute to the mission of Epilepsy Care Group (Singapore). We look forward to working with the new council to achieve an impactful epilepsy service where every person with epilepsy is empowered to live with dignity in a caring society.



Asian & Oceanian Golden Light Award Highly Commended Nominee

ECG congratulates Miss Orla Stark from Singapore for being listed as a highly commended nominee of the Asian & Oceanian Golden Light Award 2022, in recognition of her efforts in the field of epilepsy.

It is people like Orla who will really make a change for all those living with epilepsy in your region and across the world!

Read about her experiences on pages 3 & 4!



Flag Day 2023

As you may be aware, the covid-19 pandemic made it impossible for us to carry out our flag day for three years. We are elated to announce that ECG's 21st Flag Day (Physical) will be held on Saturday, 18 March 2023.

Your help is needed as tin bearers at various locations island-wide. We believe that with your help, this Flag Day would be a successful one as we strive to seek not only much needed funds but at the same time, to educate the public about epilepsy. Together, let's make a real difference!

Call us now to volunteer! Alternatively, you could send a crossed cheque payable to "Epilepsy Care Group (Singapore)" with your name and NRIC No., or donate via PayNow to UEN: S95SS0164F. Thank you.

ECG 30th Anniversary Visit to the Thailand Epilepsy Association

To celebrate the first part of ECG's 30th Anniversary in 2023, ECG is organising a visit to the Thailand Epilepsy Association. Limited places.

When: 10 April 2023, BKT 10am

Where: Queen Sirikit National Institute of Child Health (Bangkok, Thailand)

Depart from SG: Sun (9/4), 5.30pm

Arrive in SG: Fri (14/4), 11.30pm

Estimated cost: SGD1,000

There will be no subsidy. Any extension of stay will be solely on your own discretion.

Meet the Asian & Oceanian Golden Light Award Highly Commended Nominee - Orla Stark

My family and I moved from Scotland to Singapore in 2008 when I was 6-months old. When I was 8 years old, my family and I went on an outing to the Singapore Zoo. I got as far as the crocodile enclosure when I collapsed. I was unresponsive. An ambulance took me to a hospital where I was given emergency medication to stop the fitting. We didn't know I was having a seizure. A month later, I had my second seizure at school and was rushed by ambulance to another hospital which has become very familiar to me over the years. I was diagnosed with Benign Occipital Epilepsy and started taking carbamazepine daily. Apart from a couple more episodes of status epilepticus, I have enjoyed living a happy normal life. I love going to school. I love playing the cello and guitar, and taking part in school productions. Things started to fall apart as I started having numerous seizures requiring hospital admissions and my medical team was puzzled as to why the seizures had suddenly increased in frequency. They changed my medication but the seizures continued. I was in hospital having a seizure when a certain consultant happened to observe and thought I was having non-epileptic seizures. This turned out to be true, and I continued having these episodes for a few years, but learned how to cope living with them with the support of a psychologist, a neurologist, my family, my teachers, and



my friends.

I also had major knee surgery during this period to fix my dislocated knee. At this time, it took over my life. I just lived and breathed epilepsy.

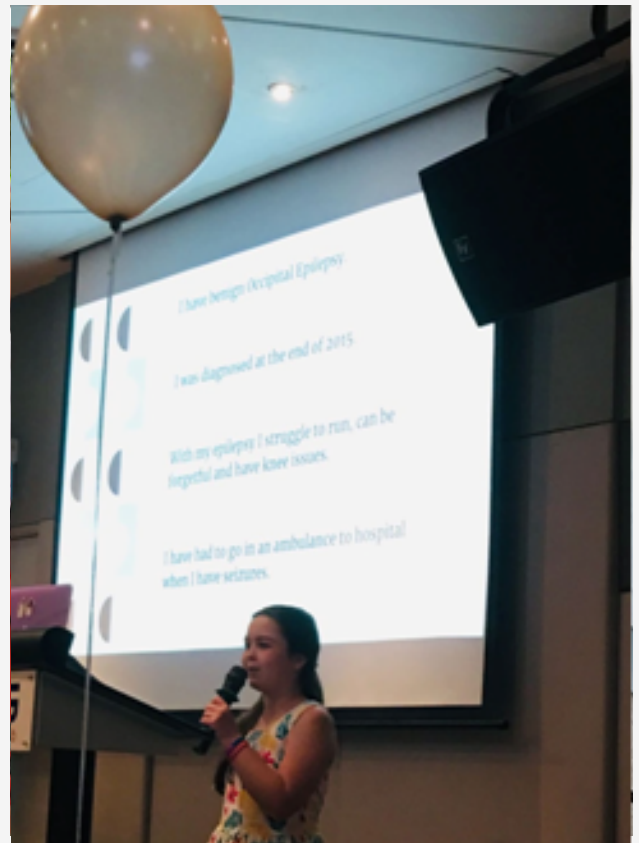
Epilepsy doesn't own or define me! I am Orla, a normal teenage girl, living life as who I am and who I always will be. Some people aren't as lucky as me, and that's why I decided to raise awareness of epilepsy and fundraise for the Epilepsy Care Group (Singapore). At my school, Nexus International School, we are always encouraged to take action about issues that we are passionate about. This inspired me to start 'PJ Day for Epilepsy.' It's a simple idea - wear your PJs to school and bring a small monetary donation for my chosen charity. It was very well received by everyone in my school and has become an awesome and fun annual event for all. In June 2022, we had our fourth successful PJ Day where learners, teachers and administrative staff

Asian & Oceanian Golden Light Award Highly Commended Nominee - Orla Stark

finished the academic year wearing their PJs to school.

I have really enjoyed raising awareness of epilepsy and sharing my personal journey with the learners at my school. I have presented at a number of whole school assemblies, and in my final year of primary education I made a movie titled 'My Road to Recovery' which was shortlisted in 2019 for the finals of the Around Asia Youth Film Festival in Vietnam. I was honoured to join the Epilepsy Care Group (Singapore) to celebrate their 25th Anniversary, and proudly got on stage to share my journey with a wonderful audience including group members and a Minister of State of the Singapore Government.

I am so grateful that my epilepsy is controlled, but I want to help other people who aren't as fortunate to feel like they are not alone in this, and that they can get through it. I hope by donating this money, it will make a little difference to these people's lives. I am very proud of what PJ Day has turned into, and I want it to go from strength to strength. I am a proud Ambassador of Epilepsy.



ECG Lunar New Year Get-together

Join ECG in celebrating the Year of the Rabbit!

When: 28 January 2023 (Saturday)

Venue: ECG

Time: 5.30pm till 8pm



ILAE/IBE 14th AOEC - Epilepsy & Society Symposium

Members of the epilepsy community gathered in ECG on 19 Nov 2022 to participate in a virtual Epilepsy & Society Symposium as part of the 14th Asian and Oceanian Epilepsy Congress (AOEC). ECG also celebrated its 29th Anniversary with a buffet lunch.

The main focus during the symposium was on the WHO's 10-year Global Action Plan on Epilepsy and other neurological disorders.

The plan focuses on strengthening the public health approach to epilepsy around the world, with a focus on ensuring access to care and protecting the human rights of people with epilepsy everywhere.

50 Million Steps for Epilepsy - Are you ready to walk with us?

PERIOD: 9 JAN - 13 FEB 2023

50 million people worldwide are affected by epilepsy. To raise awareness of this and to raise vital funds for ECG, we are asking you to help us walk 50,000,000 steps ahead of International Epilepsy Day, which falls on 13 Feb 2023. To make donations via PayNow: input UEN: S95SS0164F to "Epilepsy Care Group (Singapore)", or send a crossed cheque payable to "Epilepsy Care Group (Singapore)".



About Epilepsy Care Group (Singapore)

**ROS 226/95 WEL CA1204,
HEF0043/G, UEN:S95SS0164F**

Epilepsy Care Group (Singapore) (ECG) was established in October 1993 to address the needs and concerns of people with epilepsy, their families and those in the community directly affected by epilepsy. It is the centre of operations from which a range of services that are tailored to meet individual requirements and improve community understanding are offered.

ECG is located at:

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