

Dear members of the ILAE

Thank you for this opportunity to be considered for a position on the Management Committee of the International League Against Epilepsy (ILAE). My working experience with the ILAE during the last 15 years has filled me with deep respect for this organisation with its legacy of over a 100 years of advocating to improve the care of people with epilepsy.

I have served on multiple Commissions and Task Forces for the ILAE, with leadership roles as chair of the African Commission (2021-2025), co-chair of the Adaptation task force (2021-2025), chair of the Pediatric Commission (2013-2017), and co-chair of the Guidelines commission (2012-2014). In addition I have and am part of the following Commissions, Councils and Task Forces – Pediatrics, Global Advocacy Commission, Leadership, Education, Epilepsy Surgery, Standards and Best Practice, and Pediatric Neuropsychiatry. As chair of the African Commission in this term, it has been highly valuable for engaging with the Management Committee and understanding the needs, priorities and strategies of the ILAE.

I am a child neurologist, a clinician and work in Africa. This continent carries the highest burden of epilepsy in the world. I have experience training and working in 3 continents (Europe, Australasia and Africa), which has provided me with insight into the needs of diverse populations. Resource limited settings (RLS), which exist in low, middle and even high income countries often lack the capacity to follow international guidelines and as such these must be adapted to be viable at a local level. For many places in the world, offering standard care is a challenge, but should still be advocated for with the support of organisations such as the ILAE. The World Health Authority's resolution to approve the Intersectoral Global Action Plan for Epilepsy and other Neurological Disorders (IGAP) is already enabling us to leverage at multiple access points, strategies to improve the care we, as healthcare practitioners, offer to people with epilepsy aiming for Universal Health Care coverage.

My strategies would be aligned with the EPI-ACT. Namely promoting **engagement** across key stakeholders; facilitating strategies to strengthen **plans** from structures of epilepsy services, preventative measures, to nationally accepted protocols; encouraging the collecting of **information** to understand the burden of epilepsy eg registries; which would then lead to issues around **access** inclusive of the diagnostic and treatment gap; understanding **care pathways** is critical to exploring systems to address barriers faced by people with epilepsy and healthcare practitioners; and finally through **education and training** as this is critical to have workforce equipped to be able to actually deliver the necessary care as well as being empowered to lobby and advocate.

There is a lack of specialists confident in the care of people with epilepsy. In my centre I am director of a program, the **African Paediatric Fellowship Program**, which provides training for doctors from Africa and equips them with the necessary skills to practice with the limited resources on their return home. Attrition of the skilled labour force is a significant problem in LMICs. International collaborations can work well across more resource equipped and resource limited settings to the benefit of all but need to be carefully planned and structured.

Access to electroencephalograms (EEG) is limited in many parts of the world. Even where this resource is available, if the tool is not used appropriately it can lead to adverse interpretations for the patient. I am involved in programs to promote entry level skills for safe practice which is still necessary in many regions, and positions clinicians to then complete further training, as offered through the VIREPA courses.

Paediatric Epilepsy Training courses, established by the British Paediatric Neurology Association, are now internationally accepted is key resources to provide practitioners at the entry point of care to be equipped with the necessary skills to manage people with epilepsy. The course has been so effective that in partnership and now leadership from the ILAE there is roll-out in other languages and most recently the course has been adapted for adult neurology. Epilepsy Training in Adult Medicine (ETAM) will be the next stage for filling the gap of providing gold standard but viable approaches to care for adults with epilepsy in-line with the Primary care curriculum developed by the ILAE Academy. Whilst much of my work has been collaborating on the PET activities I am fully invested in this next exciting stage for the ETAM as well.

The **diagnostic and treatment gap** is a major barrier to care in epilepsy on a global scale. The challenges in Africa illustrate the most extreme end of the spectrum. Lack of capacity for accurate diagnoses, investigations, antiseizure medications and alternate therapies, and specialist facilities for

epilepsy care are evident globally. These challenges are related to barriers in training, education, prejudice, stigma, and finances which are not isolated to LMICS but worldwide issues. I fully support the ILAE which is a forerunner in addressing these advocacy issues.