

Dear members of the ILAE

Thank you for this opportunity to be considered for a position on the management committee of the ILAE. My working experience with the ILAE during the last 10 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 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. I support a policy whereby care is at a level appropriate for any person with epilepsy based anywhere in the world ("standard care"). Some settings may have the capacity to offer state of the art interventions ("optimal care"), often related to research or experimental concepts, these are essential to develop new and innovative interventions. But for most 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.

As part of my work for the ILAE I was part of the task force for the Neonatal guidelines (in collaboration with WHO), I chaired the task force for the Infantile seizure guidelines, co-chaired the Guidelines task force and am now chair of the Pediatric Commission. Within the Pediatric Commission we are focusing on adapting existing guidelines for local use but also collaborating with the neuropsychiatry commission to support the needs of people with epilepsy with regards to the commonly associated co-morbidities.

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 in diverse skills and equips them with the necessary skills to enable them to practice with the limited resources on their return home. I would like to encourage centres with training capacity to support the development of clinical skills. However I would motivate against recruiting fellows from low middle income countries for extended training in high income settings, unless the intent is for them to remain there. Attrition of the skilled labour force is a significant problem in LMICs. I would rather encourage specialists, willing to support training, to visit LMICs and to develop relationships with centres to promote local training and to keep international rotations to short specific periods. As part of my work for the Commission of African Affairs, as Education officer, we collaborated with the North American Commission with highly successful training programs to Zambia and Tanzania.

Access to neurophysiology 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. In my centre we have developed a clinical post-graduate diploma on basic electrophysiology and management of epilepsy in children. This provides entry level skills for safe practice and encourages clinicians to complete further training as offered through the VIREPA courses. Similar initiatives have been highly successful in Asia. I would encourage this approach starting with building foundation knowledge and enforcing the concept of safe practice.

Training and education are often interwoven. I have been part of various workshops in collaboration with the International Child Neurology Association (ICNA), the African Child Neurology Association (ACNA) the International Brain Research Organisation (IBRO), SONA (Society of Neuroscientists of Africa) and the European Academy of Neurology Regional training courses. Through these groups, in collaboration with the ILAE, we held workshops focusing on epilepsy across Africa. I would like to build on these collaborations to develop further educational workshops. Similar initiatives are highly effective in other regions such as Asia and South America. I strongly support this and encourage dissemination of knowledge across all levels of health care.

The treatment gap is a major barrier to care in epilepsy on a global scale. The challenges in Africa and Asia illustrate the most extreme end of the spectrum. Lack of capacity for accurate diagnoses, investigations, antiepileptic drugs 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 support the ILAE which is a forerunner in addressing these advocacy issues. In 2015 through the successful lobbying of the ILAE community the World Health Assembly passed the resolution to prioritise epilepsy. I would strongly support this focus on the target areas highlighted in the report.