

Dear members of the ILAE

Thank you for this opportunity to stand for the position of **regional chair for the African Commission of the ILAE**. My working experience with the ILAE during the last 14 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 full-time in Africa. This continent carries the highest burden of epilepsy in the world. I have had 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 ("gold 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 gold standard care is a challenge, but should still be advocated for with the support of organisations such as the ILAE.

During my 2 terms serving as a **member of the African Commission** I have enjoyed working with colleagues from many different regions in Africa. Finding common goals and understanding challenges to delivery optimal care. I have been involved in the coordination of the Africa Epilepsy Congresses in Nairobi, Cape Town and most recently Entebbe in 2019. This last congress especially truly illustrated the potential in Africa for neuroscience, and to promote care for people with epilepsy. This meeting brought together a breadth and depth of experience and passion for the better care of people with epilepsy inclusive of NGOs, patient advocacy groups but also basic and clinical scientists. In this pressurised world that we work in, to have a forum where these stakeholders come together so effectively is rare and powerful.

I am privileged to be a member of the **Education Commission** and involved in the development of the epileptology curriculum. This is an area that I am very passionate about. Promoting education across all levels of healthcare is essential to improve the interventions we offer to people with epilepsy. In parallel with this I have been working with the international roll-out spearheaded by the British Paediatric Neurology Association to deliver Pediatric Epilepsy Training courses. The ILAE is partnering with the BPNA. I have assisted the establishment of an African teaching faculty permitting regular courses to operate across the continent, to date reaching over 1000 health care providers. Translation of the course into Portuguese enabled the course to be run in Angola, with future plans for Mozambique. Over the current term we have been facilitating the translation of the course into French to extend access to Francophile countries in Africa especially.

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 <http://www.scah.uct.ac.za/scah/apfp>, which provides training for doctors from Africa in diverse skills and equips them with the necessary skills to enable them to practice with 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 **African Commission**, 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. Various centres in West and Sub-Saharan Africa have developed strong training capacity, namely in Dakar, Senegal. 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.

As part of my work for the ILAE **Pediatric Commission** (chair 2013-2017, committee member prior and current term) I assisted development of the Neonatal guidelines (in collaboration with WHO published 2011) and am now part of the team working on the updated guidelines, as well as the new classification. In addition I chaired the task force for the Infantile seizure guidelines (published 2015). Within the Pediatric Commission have been focusing on adapting existing guidelines for local use but have also collaborated with the neuropsychiatry commission to support the needs of people with epilepsy with regards to the commonly associated co-morbidities. This led to several reports including an assessment of the WHA in relation to the needs of children with epilepsy (2018).

**Training and education** are often interwoven. Complemented by my various roles with the International Child Neurology Association (ICNA), of which I am currently president (2018-2022), I have been part of various workshops in collaboration with the ICNA, the African Child Neurology Association (ACNA) the International Brain Research Organisation (IBRO), SONA (Society of Neuroscientists of Africa), African Academy of Neurology (AFAN) 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. I strongly support this and encourage dissemination of knowledge across all levels of health care.

The **diagnostic and treatment gap** is a major barrier to care for people with 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, 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. 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.

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