Dear members of the CAA

Thank you for this opportunity to be considered for a position on the Commission on African Affairs. 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.

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**, the group 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.

PET1 courses rolled out in Africa. The first Paediatric Epilepsy Training course was run in Cape Town, South Africa in February 2016. Established by the British Paediatric Neurology Association, the course has recently been rolled out on an international level. The Commission on African Affairs supported the development of access to the course in Africa. PET1 provides entry level assessment and management of children with seizures. The course is appropriate for any health provider faced with managing such children. The Cape Town enabled 88 delegates to complete the course and an African faculty of 36 was

established. Specifically the faculty is from across 10 African countries inclusive of South Africa, Zimbabwe, Kenya, Uganda, Tanzania, Nigeria, Ghana, Malawi, Sudan, and Sierra Leone. The aim being that courses will occur several times a year in different settings to reach as wide a group as possible. Further courses have occurred in Johannesburg, South Africa (n=63 attendees) and Kisumu, Kenya (n=52 attendees), more courses will occur in South Africa, Tanzania and Uganda over the next 18 months.

The **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, 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.