The role of ICNA in Africa

The 11th International Child Neurology Congress was held in Cairo in May 2010 and provided a unique opportunity for African neuropediatricians to share their experiences and establish collaborative networks. During this meeting, the African Child Neurology Association was founded, with the aim to identify training facilities in Africa and propose guidelines for resources, standard of care, and clinical research. The child neurology needs in Malawi, Uganda, Ghana, and Nigeria were identified. Based on these discussions, the International Child Neurology Association (ICNA) will hold a 3-day educational workshop in Uganda in early 2012 to discuss children with epilepsy in sub-Saharan Africa.

The topic 'children with epilepsy' was selected as the focus of this workshop for several reasons. It is estimated that 20% of the 50 million people worldwide with epilepsy live in Africa.[1] Most of the epilepsy in this region starts during childhood, and estimates of the prevalence of epilepsy in African children range from 3 to 26 per 1000 children. In Kenya, an incidence of epilepsy was reported as 187/100 000/year with a prevalence of active epilepsy of 11/1000.[2] By the age of 6 to 9 years, 4% of children had developed epilepsy and most (89%) were not receiving antiepileptic medication. Furthermore, nearly half had other impairments (particularly cognitive) and were less likely to attend school. In another large survey involving 151 408 individuals with epilepsy in Kenya,[3] the treatment gap was an astonishing 70.3%. The causes for this gap were inadequately skilled manpower, cost of treatment, and unavailability of antiepileptic drugs. While most countries have access to general pediatricians, few have pediatric neurology services.

In another survey of pediatric neurology services involving 15 African countries, key areas of need were identified as training and education at all levels. Training is more appropriate in centres in which the conditions and issues of management are similar to the trainee's country of origin. Such programmes are established in South Africa for doctors from other parts of Africa, and to date all trainees have returned to their referring country.

The first point of contact for children with epilepsy in Africa is not optimal, as few countries have a clear referral system. Patients can present to many different people, from the traditional healer to specialists in tertiary centers. However, most patients present to primary health care workers or medical officers. The level of training in the recognition and management of epilepsy of this group is very variable. Responses to the survey included requests for *training and referral guidelines*. The diagnosis of epilepsy is made in most African countries by a medical officer. The primary health care worker may suspect the diagnosis but often must wait until a pediatrician confirms it. In most African countries, government-employed pediatricians are few, and management may be delayed. In the survey, only two out of 15 of the countries had national guidelines for epilepsy management in children. Thus, one of our goals is to work with each country to set up National and Regional Guidelines which would allow lobbying for facilities and medications, and would be appropriate to the capacity of the country. Indeed, in the proposed 3-day program, one full day is set aside for this type of working session to establish firm guidelines for the comprehensive management of children with epilepsy.

At present, in many African nations, the main treatment available for epilepsy is phenobarbitone (phenobarbital), and access to other agents is either not available, or not reliable, for the vast majority of patients that cannot afford private medicine. The treatment gap varies from 48 to 96% in the region,[4] with children accessing treatment less frequently than adults.[3] Access to electroencephalography (EEG) is limited and even when available, the interpretation is often inaccurate, particularly for children's EEGs. Although neuroimaging (computed tomography) is available in most countries, this service is often restricted by location and cost implications.

In many African countries the incidence of status epilepticus is over five times that found in Western countries and its management is simply repeated doses of diazepam. The supply of injectable phenobarbitone is erratic and few hospitals have phenytoin. Access to paediatric intensive care units is almost non-existent. Optimum care is also challenged with few centers having syringe drivers, saturation monitors, suction pumps, or ventilators.

The ICNA workshop will have the following goals: (1) To establish an educational platform in child neurology for a group of strategically selected doctors from diverse regions in Africa. (2) To empower these doctors to build awareness of optimal epilepsy management. (3) To empower these doctors to return to their centers of practice and to lobby for optimal facilities. (4) To identify needs across Africa for the optimal management of children with epilepsy. (5) To develop a working group who will continue to promote optimal care for children with epilepsy.

As part of its educational mission,[5] ICNA has established a child neurology portal 'ICNApedia' at http://www.icnapedia.org. This interactive knowledge environment website coordinates ICNA's educational and research activities and facilitates communication among users to establish and expand a professional network of child neurologists across the globe. One of the goals of the Uganda meeting is to teach participants how to take maximum advantage of ICNApedia. This portal will also be used, after the meeting, to continue the dialogue with participants and assess progress in their efforts locally.

It is hoped that this workshop will be the first regional initiative to address the needs of children with epilepsy, to improve their care, and promote social integration.

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