Meeting report

Children with Epilepsy Meeting February 2-4th 2012

International Child Neurology Association / African Child Neurology Association

Executive Summary and Outcomes

1. 19 Countries from Africa represented
2. Cohesive working group established, including a further 9 African countries n=28
3. Report of findings and summary attached
4. Attendee activity and program summary attached
5. Presentations and discussions video-audio recorded and accessible on the ICNApedia website

The next stage – based on the findings from the meeting the following will be addressed:

1. **Research:** Publish the findings from this meeting, combined with the updated child neurology services data.
2. **Resources:** Develop a single web-page which summaries links to all internet resources to aid in the practice of, or training skills needed for, managing children with epilepsy – located on the ACNA section of ICNApedia but interfacing will all major groups (e.g. ILAE, WFN, AAN, BPNA, EPNS etc)
3. **Resources:** Collate the recognised guidelines used in the management of epilepsy, dissipate these to all countries from the group and interrogate in more detail their viability
4. **Education and Training:** Train the specialists - develop training initiatives within Africa, relevant to the continent – collaborate with "out of Africa" specialists and centres to promote this training for specific skills development. E.g. http://www.scah.uct.ac.za/apfp/ and Visiting Professor program. Establish a critical mass of at least 1:100 000 as per WHO recommendations for adult neurology (currently estimated at 0.03:100 000 adult neurology), for paediatric neurology figure is far below this.
5. **Education and Training:** The specialists must undertake the responsibility for driving training and awareness of epilepsy management in their countries – at all levels of health care. Developing educational programs in collaboration with the department of education, department of health and NGOs. Address concepts of stigma, prejudice and misconceptions (e.g. epilepsy is contagious).
6. **Innovation / lobbying:** Develop workable guidelines / recommendations for all countries – use these for lobbying
7. **Innovation:** Support the concept of "epilepsy teams" – involve traditional healers in this program. The regional specialists train these working teams with the requested input from other centres. But the exercise is driven from within the country.

8. **Innovation:** Challenge policy to ensure that it is the right of the child with epilepsy to have access to AEDs. Evolve this concept to expand the range of AEDs. Initially start with reliable supplies of Phenobarbitone but constantly challenge the right of the child to agents with less side effects. Ensure there is health care equity between the rural and urban settings.
9. **Innovation:** Establish an internet based referral system for complex patients from RPCs to be discussed in a central forum and consultation provided by voluntary experts in the field.

Further meetings 2013

1. Based on the survey of the delegates the theme requested for 2013 is **cerebral palsy**.
    a. As before data will be recruited from the working group beforehand to understand needs and directions to gain optimal outcomes for the meeting
2. To maintain the continuity **feedback on the progress from the Epilepsy meeting** will be addresses
3. To expand the knowledge base of neurological conditions managed in the African continent **Movement disorders** will also be addressed.
    a. A survey will also be undertaken to assess the range of movement disorders seen across the continent and what interventions are made in response.

Budget from 2012 meeting

Venue and accommodation:	$21,568
Flights: for n=16 delegates (remainder self-funded either via local institutions or as ICNA board members)	$18,504
Epilepsy books	$425
Mediavision Productions Ltd (Audio-Vision)	$1,233
Total:	**$41,730**

Donations: Sanofi Aventis (SA branch) donated writing pads, folders and pens.

Meeting report

Children with Epilepsy meeting February 2-4th 2012

International Child Neurology Association / African Child Neurology Association

In February 2012 a group of dedicated doctors from 19 different countries in African, and a further 5 countries outside Africa, met to discuss issues affecting the management of children with epilepsy in Africa.

Attendees from Africa: Luis Bernadino and Manuel Cruzeiro (Angola), David Bearden (Botswana / USA), Elie Mbonda (Cameroun), Therese Douayoua-Sonan (Cote d'Ivoire), Luc Malimbalimba Maururu (DRC), Ahmed Raouf Ibrahim (Egypt), Kindu Woldemichael (Ethiopia), Eben Badoe (Ghana), Pauline Samia and Charles Newton (Kenya), Macpherson Mallewa (Malawi), Dalila Ibrhimo Sulemane (Mozambique), Wammanda Daniel Robinson (Nigeria), Judy Orikiiza Tatwangire and Febrionie Mushimiyimana (Rwanda), Moustapha Ndiaye (Senegal), Alhaji Alusine Jalloh (Sierra Leone), Jo Wilmshurst, Andre Venter and Gail Scher (South Africa), Haydar El Hadi Babikir (Sudan), Angelina Kakooza and Richard Idro (Uganda), Evans Mpabalwani (Zambia).

From outside Africa: Harry Chugani, Deborah Hirtz, Douglas Postels, Pamela Follett (USA); Helen Cross and Cheryl Hemingway (UK), Lieven Legae (Begium) and Mitsuhiro Kato (Japan).

The program commenced with basic approaches and mimics of epilepsy, and then progressed to discuss more complex issues such as epilepsy surgery. The final day focused on the way forward and covered how information technology resources and non-government organisations can be used. The final part of the meeting consisted of dividing the attendees into small working groups who discussed key themes which had arisen during the meeting namely capacity, definitions, guidelines, and training and education needs. Each theme was summarised by one of the African delegates who co-facilitated a working group.

The meeting was recorded, the videos of the presentations are available on the ICNApedia web-site (www.ICNApedia.org) along with the power-point presentations (after the patient and data confidentiality was addressed).

The presentations were delivered by members of the International Child Neurology Association (ICNA), African Child Neurology Association (ACNA), International League Against Epilepsy (ILAE), National Institutes of Health (NIH), the Japanese Child Neurology Society and the delegates.

Twenty-eight countries provided information on their **services, capacity and approach to children with epilepsy**. Thirty-three delegates from 19 of these countries were able to attend the meeting, those who could not expressed eagerness to remain part of the working group. A further five specialists from countries outside Africa (United Kingdom, United States of America, Belgium and Japan) attended the meeting.

The presentations were dynamic and interactive. The most productive parts were the discussions which followed each presentation, these were often extensive and the meeting overran everyday – this was regarded as a success and illustrated the enthusiasm of the group!

Key themes which repeatedly arose centred around resources, training needs, education and innovative approaches needed to maximise access to health care.

When assessing **access to services** some countries have dedicated child neurology clinics, but this often equates to one for the whole country as is the case for Zambia.(1) The group highlighted the need to ensure insight into early recognition of epilepsy and the capacity to provide basic management approaches. Both of these areas are lacking in much of Africa. Elie Mbonda from the Cameroon commented that many children are further disadvantaged when in **rural settings** as the facilities are even more limited there.(2)

In a number of the countries epilepsy is managed by **psychiatrists,** there is little in the literature to support this but the statement was confirmed by many of the delegates – especially those form Zambia, Uganda, Ghana and Nigeria**.(3)** Although this has its benefits for the co-morbidities, the added stigma of a patient diagnosed with epilepsy attending a psychiatrist is a negative outcome. Further psychiatrists tend not to be trained in the most up to date interventions for epilepsy. The patient is more likely to be managed with a behavioural remedy. However there are many more psychiatrists practicing in Africa than paediatricians or neurologists, and most definitely child neurologists.(1,4) This raises issues of the practicalities of removing the care of these patients from this group. Some form of transition or co-management may be a better option and locating epilepsy clinics outside of a psychiatric clinic. Helen Cross pointed out that the Mental Health guidelines published by the WHO www.who.int/mental_health/mhgap included epilepsy in this document. This was because the needs of both areas overlapped and as such, centres could complement services with parallel care. She agreed the issue of stigma was a major challenge which needed to be addressed. Kindu Woldemichael commented that in Ethiopia their EEG machine is in the psychiatry unit. Eben Badoe from Ghana raised another issue to complicate this transition, in his country according to the Mental Health act, antiepileptic drugs (AEDs) are free for patients managed by psychiatrists. In his context if this transfer of care were to be successfully undertaken then the access to medications would need to be guaranteed to continue.

The role of **traditional healers** was raised by Charles Newton. The traditional healer is the first point of contact in most situations in Africa and although most traditional healers will admit an inability to treat epilepsy the patients still prefer to use them.(5-7) The reasons for this included that they were more widely available, traditional healers vastly outnumber health care workers and the fees can be paid in various ways (chickens are fine). The healer will spend several hours with the affected person and the family, so such they provide a huge amount of emotional support. The doctor is rarely in a position to do this and this potential psychosocial support should not be underestimated. Studies from Zambia illustrated the high level of observational and descriptive skills attained by traditional healers.(8) In a number of countries the medical services have attempted to work with the traditional healers and have met in most cases with positive responses e.g. Cameroon, Tanzania and Kenya.(5-7) A number of the healers agreed to refer patients with epilepsy on to the medical services but they also pointed out that it was unacceptable that the medical services never referred them back. Considering the significant support this group would have the capacity to offer, including them in the management of epilepsy would clearly be a huge resource specific to Africa.(8)

Charles Newton discussed access to and the **role of neuroimaging and EEG** in Africa. He stated that based on the ILAE guidelines there is a role for EEG in Africa.(9) The continent suffers far more symptomatic, or structural insults, than seen in resource equipped countries. In addition the prevalence of epilepsy is far higher in Africa, twice that of Asia.(10) This extends beyond the acquired insults into the concept that certain population groups seem to be more predisposed to suffering from epilepsy as well.(10) As regards neuroimaging – there are good indications to support the role for neuroimaging in Africa as illustrated by ILAE.(11) Access remains a challenge compounded by the quality of the studies performed on old, out of date machines, and limited access to competent interpretations by trained experts. Beyond this the cost is prohibitive in most parts of the continent. Harry Chugani followed on with a further talk on neuroimaging. He offered the DTI software for free which had been developed and patented by his own unit. This would assist in the potential development of centres equipped to undertake epilepsy surgery who would ideally require functional MRI, MRS, as well at PET. The latter is a truly scare resource in Africa, there are 2 PET scanners in South Africa, for the remainder of the continent the number is not known. Harry pointed out that if a unit was committed to gaining an MRI the ideal would be at a 1.5 Tesla for the best results –once 3T or even 7T are introduced the cost benefit for the African setting becomes more limited.

For **maintenance treatment of epilepsy** those children who are recognised to have epilepsy, and are able to access a health facility, in most parts of Africa are initiated with phenobarbitone.(12,13) In parts of Kenya up to 89% of children with epilepsy are not recognised and left without any treatment.(14) Heated discussion followed along the lines of whether some form of therapy was better than nothing, challenging the concern of unacceptable side effects from the antiepileptic drug (AED). The ideal would be to have other first line agents more readily available namely sodium valproate and carbamazepine. The cost of the former precludes ready access of the AED in many countries – of interest the actual cost also varies widely across the continent reflecting different marketing strategies and raises the issue of unethical profit making by pharmaceutical companies (www.who.int/entity/mental_health/.../**epilepsy**_in_**African-region**.pdf). The group agreed that in an ideal setting every child found to have epilepsy should have access to the AED with the least side effects, most cost efficacy and most efficacy for seizure control. Governments should be lobbied with this in mind.

Following Lieven Legae's presentation on **co-morbidities** Angelina Kakooza (Uganda) commented that beyond the co-morbidities associated with epilepsy the stigma in addition puts the children at a huge disadvantage. For example the policy of inclusive education in Europe means that children will be included and supported in mainstream education. In Africa there is a high chance that the child will not be allowed to remain in mainstream education or even accepted as part of the local community.(15,16) (www.who.int/entity/mental_health/.../**epilepsy**_in_**African-region**.pdf) Although there is overlap in the service needs for patients under psychiatry and child neurology for children with epilepsy the responsibility and management must be directed by child neurologists. In reality child neurologists must become more insightful of these co-morbidities and how to manage them best. All means should be used to avoid the inevitable stigma of suffering from epilepsy. Perceptions need to be changed. In Uganda there have been challenges transferring children from the psychiatric service – these practitioners enjoy looking after patients with epilepsy. Children are often on a cocktail of medication including haloperidol in addition to AEDs. Patients frequently "shop around" leading to further polypharmacy and poor compliance.(3)

When assessing practice and resources the group concluded that in the management **for infantile spasms** (following the presentation by Mitshiro Kato from Japan) that prednisone was the main acute intervention used. However most centres were unsure of the optimal regime with no consistency in their practice. The NICE guidelines may provide an evidence based approach which should be viable to follow in much of Africa (www.nice.org.uk/cg137). It is expected that the combination of dual therapy with prednisone and vigabatrin will be one possible regimen. Harry Chugani commented that use of taurine with vigabatrin seemed to result in reduced visual field deficits in animal studies.(17) In most of Africa the diagnosis of infantile spasms is often delayed and based on clinical assessment.

Richard Idro (Uganda) presented data on **cerebral malaria**. This neuroinfection is prevalent over most of the continent and results in major acute and chronic complications. The acute management is further challenged by poor outcomes with standard antiepileptic agents. Intravenous levetiracetam is being explored but the viability in the African context for this is debatable. This led to huge debate about resources and the fact that if a guideline is then developed promoting the use of an expensive agent such as parenteral levetiracetam that this will be not available for the centres which most need it. However if the study Richard is referring to (results pending) confirms a significantly better outcome for affected patients who are managed with this agent then one can challenge that it becomes unethical to limit access, and specialists must lobby for the treatment to be available. The cost comparison of administering parenteral levetiracetam for acute seizure management would need to be compared to the lifetime of caring for a child with a neurodeficit due to inadequate care. Additional challenges following cerebral malaria are the behavioural complications – Macpherson Mallewa from Malawi has had good results using ritalin. Charles Newton pointed out that the true incidence of cerebral malaria is not known as most encephalopathic patients across the continent do not have access to cerebral spinal fluid analysis. In addition co-infection is very common, for example in Malawi with rabies.(18)

David Bearden, who works as the sole paediatric neurologist in Botswana, rotating between his post in Philidelphia, presented his work on **HIV and epilepsy**. He is currently in the process of collating the figures for publication. HIV is prevalent across Africa and influences all aspects of child health. Macpherson supported David's presentation agreeing that most of the AEDs routinely used in Africa (phenobarbitone, carbamazepine and phenytoin) are the ones with major interactions with antiretroviral therapy (ART). David commented that patients who have access to a tertiary centre will be managed with safer combinations such as sodium valproate. This also raised the argument for weaning children from AEDs as soon as possible to limit drug-drug interactions. Pauline Samia from Kenya commented that as part of her work in Cape Town she had completed a similar study to David – it was fascinating to note that her findings were very similar – it is hoped that both publications could complete and be published at the same time as they complement each other. She also commented that in adult practice lamotrigine is promoted as the first line agent, this has been avoided in South Africa (as a first line intervention) as the rash is more likely to occur in children and additionally so in the context of HIV. Even sodium valproate is not without complications there have been several children on efavirenz who suffered potential treatment failure due to the drug-drug interactions and needed to be converted to nevirapine.

In his talk on **metabolic disorders with epilepsy** Lieven Legae commented that for “simple” but effective interventions even in resource limited settings a trial of pyridoxine should be considered in young infants and children with epilepsy. In addition diagnostic clues should be noted such as skin changes and dysmorphology. Although he raised the ideal of establishing neonatal screening programs he acknowledged that the infrastructure to support this must also be in place. Harry Chugani pointed out how internet resources could be used as central forum to present **unusual patients**. Several such resources already exist but it may help RPC to use ICNApedia as a conduit to gain focused rather than random opinions. During the meeting it was evident that **second opinions** and expert advice was often sought across the continent. There was rarely a pattern or system to this and the requesting centre had little idea if the “expert” was truly the optimal person or just some international practitioner doing a favour. There is a need to strategise this random system of referrals both to ensure good clinical practice is maintained and to ensure that optimal care is offered for the child. If such a system occurred via ICNApedia, the advice sent back to the referring centre could be provided from a list of volunteer experts who are networked into an extensive potential resource capacity i.e. they could provide true expert advice in a systematic and consistent manner.

Cheryl Hemingway presented data on the **Ketogenic diet**. This therapeutic approach for patients with difficult to control epilepsy led to much discussion. Charles Newton pointed out that in countries with a high carbohydrate based diet it is very difficult to maintain the patients in ketosis, as a result the diet works better in India for example.(19) This was illustrated in Kenya where attempts to introduce the diet have failed. In Botswana the diet has been introduced but in the form of the modified Atkins diet which seems to be easier to maintain, but despite this has been challenging and there are problems with the monitoring. Richard Idro agreed that the African staple diet is not compatible with the KD, it is expensive and the high fat based content cannot be sustained. The program does not work without a trained dietician who is readily available. Haydar Babikir from Sudan commented that the diet also has a major effect on the mother to child interactions and behaviour – this in itself can put huge strain on the family. Cheryl agreed the diet is a way of life. The ketogenic diet is used at Red Cross Children's Hospital in Cape Town. Patients are carefully recruited and counselled – they are admitted in groups to the ward for a week of intensive initiation and training with the main carer resident – the main work of this falls to the dietician who must remain accessible throughout the time the child is on the diet. The additional expense of being on the diet is covered via reimbursement to the family from the fund raising department at the hospital.

Helen Cross presented some fascinating data on **epilepsy surgery**. There are very few centres in Africa with the capacity to perform epilepsy surgery in children.(20,21) Charles Newton commented that there are an estimated 16 000 patients who could benefit from epilepsy surgery across the continent. This was based a population of 1 billion, and an epilepsy median incidence 80/100,000/year, and about 2% of patients with epilepsy who could benefit from surgery (100,000,000 x (80/100,000) x (2/100) = 16,000 per year). In reality this figure is probably even higher in Africa. Ben Badoe from Ghana presented a patient with intractable epilepsy who needed epilepsy surgery. This resource is not available in his centre. He is now in contact with some of the international speakers to try and coordinate this. He had been attempting to coordinate a referral to an international centre but that without some form of **structured referral system** this tends to become random and potentially dangerous.

Helen Cross presented data on **Epilepsy Genetics**. This resource is completely lacking over the majority of Africa. Despite this she clarified that at the current time genetic diagnostic closure does not influence patient management. In the future there may be a case for pharmacogenetics. There are some situations where confirmation of the diagnosis of one of the severe infantile seizure disorders would allow for prenatal counselling. For many of the severe neonatal and infantile seizure disorders the clinical and neurophysiological semiology is diagnostic.

The talk on parasitic infections raised much debate about **health care structures** and the need for **primary prevention** – how the impact of fairly minimal interventions resulted in significant reductions on conditions such as neurocysticercosis following the penning of pigs in certain regions. This promoted the role specialists can have in lobbying for improved practice at a primary level which is not costly but results in huge gains to the health of the region.

Alhaji Alusine Jalloh from Sierra Leone described the benefits of an **educational program** communicated via the radio. This targeted a huge proportion of the population and resulted in their epilepsy service having to operate a continuous clinic for 4 days to catch up with the flood of concerned persons. They have also looked at ways to access medications which would otherwise be beyond their patient's reach for cost reasons. They have outside funding which permits them to supplement of the AED costs. Although the patient must still pay a fee it is considerably cheaper than on the open market. This also has the benefit of encouraging the patient to regularly attend the clinic leading to better compliance.

Judy Tatwangire from Rwanda commented that epilepsy is by far the commonest condition she manages in her neurology and paediatric service. She commented on the role of **scarification** and two thirds of the group responded that it is an accepted intervention in their countries.(22)

The last day commenced with an exciting presentation by Helen Cross and Cheryl Hemingway with data from Biju Hameed on the topic of **Internet Resources**. The ILAE provide www.ILAE.org *classification,* teaching resources including VIREPA *EEG, imaging, genetics, pharmacotherapy. The* ICNA uses ICNApedia.org as its major teaching and educational online resource with journal watch, audiovisual presentations and neuroimaging examples. Treatment of NEonatal seizures with Medication Off-patent (NEMO) is a similar organisation (http://www.nemo-europe.com/en/educational-tools.php). The BPNA has a Distance learning course, 2 doctors from Kenya are currently registered for this. The course requires a local supervisor – this task in shared between Pauline Samia and Charles Newton. There is a fee, although this is reduced for doctors from resource poor countries. The WFN also have on-line learning tools, affiliated with the American Academy of Neurology. Other resources include eBrain (eBrain.jnc.com) which is free but covers adult topics, and Ketogenic diet resources. Associations such as the ICNA should have allocated funds to support these endeavours. Douglas Postels with support from WFN is in the process of devising educational tools which will consist of series management algorithms, these will be widely available via providing the data on flash drives which can be circulated to all levels of care, primary to tertiary. Cheryl described another program devised by the BPNA called PET (Paediatric Epilepsy Training) – a series of teaching courses are run and the local centre trained to take over the course. There are 3 levels and group will adapt the course for the region it is presented in. After its successful introduction in the UK the group looking at the potential of extending the program abroad.

Charles Newton presented on the **treatment gap**.(12) He noted that there are many more traditional healers who are seen to offer a more holistic approach. Within the Kilifi areas of Kenya there are a number of healers with a special interest in epilepsy. Patients with epilepsy did not like attending the hospital even if the medication was free due to the impact of loss of time from work and the cost of the travel. As a result the adherence to the medication was terrible with therapeutic levels often at zero. He concluded that better collaboration with the traditional healers was essential. He addressed the mental health and psychiatry issues which were terribly important – it is not unusual for patients with epilepsy to suffer from one or both of these co-morbidities. His group have started to encourage the support of an identified carer for all adult patients. It is clear that even with these concepts in place that there is a great need for better education and access to AEDs. In the discussions which followed, how to raise the awareness of epilepsy was raised. Charles agreed with the use of radio stations and also to maintain the contact the cell phone is probably the most widely available electronic device across Africa. Text messages and reminders could be fairly easily set up. Further the involvement of the traditional healers is essential – not just encouraging their referral of patients to the facilities but the respect to send the patients back to the healer for combined care where they will often receive psychosocial support.

Pauline Samia (Kenya) and Angelina Kakooza (Uganda) presented data on **Non-Government Organisations (NGOs)** and their roles in their countries. They supported previously noted comments on the efficacy of radio broadcasts to raise awareness and education the population. NGOs play a major role across Africa – these are listed under the International Bureau for Epilepsy (IBE), examples are the Kenya Association for the Welfare of People with Epilepsy (KAWE) and Epilepsy South Africa (Ep SA). Haydar Babikir from Sudan commented that access to therapies and facilities is challenging and distances of up to 200 miles to get to a centre are not unusual. He has been part of Epilepsy Care Programs which have successfully operated for the last 4 years in Sudan. They have attempted to overcome some of the challenges set by religious issues and the stigma of epilepsy. Traditional healers in his country can be resistant to "modern" medicine, the program has been integrating traditional healers and making them part of the management team. Angelina described how to Epilepsy Support Association in Uganda started very small initially with by a single social worker. His fund raising eventually allowed a whole building to be developed with administrative staff and further support staff. The group focus on advocacy for people with epilepsy both through direct support and educational programs. Staff "work in the field" they actively approach the community with educational programs and making epilepsy more visible. They act as a link with the tertiary centres. They support mobile clinics, transporting a doctor to needy areas and to provide free health care and counselling. The Association assists with defusing various myths – including a recent misunderstanding over pork – without the information provided there could have disastrous consequences. Angelina commented that it takes great courage, especially in Uganda to declare that you have epilepsy as there is so much stigma associated with it, they have been following the trends from other countries such as South Africa where leading sports persons who are affected act as figure heads to raise the profile and acceptance of the condition from the community through to national level. The ILAE and IBE staff often hold their combined meetings at the NGO office in Kampala. Charles Newton commented on the importance of developing self-sustaining income generating schemes as external funding tends to be intermittent, inconsistent and not always reliably maintained.

Helen Cross pointed out the WHO / IBE / ILAE **"Global campaign against epilepsy"** was an excellent example of a collaborative initiative. (www.who.int/entity/mental_health/.../**epilepsy**_in_**African-region**.pdf) The group could support further projects along this theme. A recent example of completion of such a Demonstration Project has been in Georgia where a group established the degree of the problem, devised an intervention and are now reviewing their outcomes. The next stage is to assess the sustainability based on the epidemiology of epilepsy and management efficacy. They have set up clinics providing cost effective medication and information. The funding for this program has predominantly been from the local government with minimal support from the WHO – the aim being to establish sustainability. Currently the possibility of similar projects are being explored in the Cameroon and possibly Ghana. The programs approach adult and paediatric epilepsy needs.

Jo Wilmshurst presented a summary of the challenges of establishing **training centres** and addressing the **training needs** of specialists across Africa.(1,4) The concept of the brain drain is not new and Africa suffers from this to its detriment.(23-26) The group agreed that training should be promoted within Africa by Africans to keep the training relevant to the health needs of the region. Overseas training should be focused into specific targeted skills development.

Following the formal presentations and discussions generated, the group broke into four workshop groups covering the following themes. Each delegate rotated and was able to make comment at each workshop.

Basic care levels and Capacity in Africa – this was to assess how the interventions and presentations compared to the realities of capacity in much of Africa. This workshop was facilitated by Robinson Wammanda, Charles Newton and Pamela Follett. Their summary concluded that the major challenges revolved around the lack availability of AEDs. This involved multiple points including the scope of drugs available and the cost relating to second line therapy. In addition the lack of consistent availability of even the standard drugs (phenobarbitone, phenytoin carbamazepine and sodium valproate), especially in clinics outside cities where it was common to run out mid-month leaving no available treatments. This was often due to inefficient administrative controls, lack of standard operating procedures (SOPs) and limited options to buy from alternative suppliers as they were required to use government tender suppliers who were unreliable. As such policy changes which would increase availability, particularly in remote areas would be important.

As regards personnel there was a need for training at all levels. The social perceptions and stigma must be targeted so that people with epilepsy can be recognised and treated. The need to challenge the stigma, and the perception that epilepsy is a curse and not a medical problem, was a common problem across much of Africa. This meant that promoting the insight that the condition should be treated was a further issue.

The role of traditional healers should be further explored for their additional involvement in the management of patients with epilepsy as they are often the preferred providers and the most accessible. The lack of National guidelines was viewed as a major challenge to lobbying for better practice. Where guidelines are in place, they should be used and where not, they should be introduced. There is a need for an established assessment of the Burden of Disease in Africa and its social impact, further there is great need to truely understand the aetiologies of epilepsy in Africa. Without this epidemiological data, lobbying for specific services cannot be effectively undertaken. The assessment concluded with the suggestion that there should better education on epilepsy from the community to the health care level. That groups should speak with a common language such that there is a consistent message which is put to governments who are encouraged to be part of the process.

Definitions – There is a lack of knowledge of the true prevalence of epilepsy in Africa and the recognition of what is a seizure. Many centres struggle to recognise events beyond generalised tonic convulsions and even these are often misinterpreted. Further defining how patients with intractable epilepsy is challenging, especially when they do not have access to medications beyond phenobarbitone, and there is resistance to medical interventions due to local concepts. This group was facilitated by Cheryl Hemingway and Macphersen Mallewa. They targeted the concept of "what is epilepsy" – they defined it as a chronic neurological disorder characterised by recurrent epileptic seizures as defined by the ILAE. www.ILAE.org However they challenged the terms "chronic" and "epileptic" and suggested that "unprovoked" was a better term – although this then excluded the reflex epilepsies. As regards the definition of a seizure, according to the ILAE description it is based on the assumption that an EEG has been performed. www.ILAE.org This is difficult in the African context and the description becomes more appropriate for a convulsion, a seizure or a fit rather than epilepsy. The definition of drug resistance is also very difficult to fit into the African context with inadequate training and access to AEDs as well as compliance issues.

Current guidelines and recommendations. The workshop was facilitated by Helen Cross and Angelina Kakooza. Extensive and well thought-out guidelines and recommendations exist. The majority are impractical and non-viable for Africa . The facilitators rapidly realised that many of the group did have access to these ILAE www.ILAE.org or NICE guidelines (www.nice.org.uk/cg137)and that they would have had great difficulty following many of them. Guidelines and recommendations as they are devised need to be scrutinized by health care workers in resource poor countries to ensure that they are viable in each centre. In this process of guideline development it is critical to ensure that as an ethical issue that the rights of the child are up held. If there is an intervention which is clearly the ideal approach then a sub-optimal level of care should not be accepted because the child is from a RPC. Any guideline should be equally effective for children regardless of their setting, the guideline can be extended to include the concept of "optimal care" such as fourth generation drugs and complex neuroimaging, but it is the ideal care which should be equivalent for a child anywhere in the world

Training and Education. There is word of mouth knowledge about the number of child neurology training centres with the capacity to train to an international level within Africa. In reality this number is probably under five, as such there is a great need to expand this figure. In addition diverse training and educational programmes are needed to develop greater awareness of epilepsy across the continent. The workshop, led by Pauline Samia and Jo Wilmshurst questioned the various groups about the amount of undergraduate training time that is dedicated to neurology, child neurology and epilepsy. The range was inconsistent and diverse with anything from a few lectures in the whole curriculum to 3 month attachments within neurology services. Focused teaching on epilepsy at undergraduate level did not appear to be of high priority at the undergraduate level. Many undergraduates were qualifying with potentially 1-2 hours of teaching on epilepsy throughout their whole medical degree course. The Integrated Management of Childhood Illness (IMCI) does not have a separate section addressing epilepsy or the management of acute seizures http://whqlibdoc.who.int/publications/2005/9241546441.pdf.(27) Lobbying to include this theme in the IMCI would ensure that the recognition, and the acute management of seizures, is taught to wide range of health care practitioners. In a number of countries including Malawi and Sierra Leone, post graduate training in paediatrics within the country is not available hence few paediatricians are available. Training to create a critical mass of paediatricians may need to be addressed first before training of child Neurologists can be planned. The WHO mental health gap intervention manual (www.who.int/mental_health/mhgap), for mental, neurological and substance abuse disorders in non-specialised health settings, addresses epilepsy in detail but this extensive text is under circulated and not well utilised in most settings based on the lack of awareness of the document in the workshop. The group agreed that education and teaching at the primary health care level was essential to target early recognition and intervention of epilepsy. However the role for coordinating this must be through the most qualified individual from within the country. These specialists would benefit from overseas support but the direction of the secondary and primary level teaching, in their own country, must be led by them since they would be the best person to have insight into ideal way to work with the known infrastructure.

Discussion and conclusions:

Several consistent themes occurred throughout the meeting.

For **resources** the use of the traditional healer is a major untapped resource, this could help with capacity where the numbers of health care worker are scarce. Better communication between the primary health care centres and the tertiary units, using the NGOs to facilitate this.

Training was desperately needed at all levels from primary to tertiary level.

Education required innovative approaches to raise awareness such as radio programs. Also to make the access to on-line resources better known and more available. Specific target groups where the most benefit will occur should be involved.

The use of **guidelines** needs to be more widely incorporated again raising awareness, assessing how appropriate and viable they are in the African context and adjusting them for African practice to use as lobbying tools to ensure ideal care is provided.

There is a great need for comprehensive **epidemiological studies**. Without these effective lobbying cannot be undertaken – the facts must be defined and the guidelines accepted.

Lastly the role of **psychiatry** is contentious in a setting where there are far more psychiatrists than even paediatricians, let alone child neurologists rather than removing all children with epilepsy from their care it may be better to work with these groups to move them for their clinics of patients with epilepsy away from the psychiatry until into more child friendly environments and to ensure that the prescribing practice follows child neurology guidelines.

The group concluding that they were keen to meet again and to remain in contact following the meeting. The vote from the group for the next topic included the topics cerebral palsy, epilepsy (again) and CNS infections. Themes around **cerebral palsy** were selected as the next most needy area addressing similar challenges as covered in this meeting namely definitions, access to care, differentials and guidelines. The next meeting will be held in one year in Cape Town and will also provide an update of progress on epilepsy based on the current meeting.

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