

## **ILAE-Africa**

### **2022 Annual Report**

#### **EXECUTIVE BOARD MEMBERS**

Jo M. Wilmshurst (South Africa), chair  
Angelina Kakooza-Mwesige (Uganda), past chair  
Naluca Mimi Mwendaweli (Zambia), YES representative  
Augustina Charway-Felli (Ghana)  
Adjien Kodjo Constant (Benin)  
Dominique Enyama (Cameroon)  
Edward Nkingwa Kija (Tanzania)  
Youssoufa Maiga (Mali)  
Vivian Namale Ssonko (Uganda)

*Nursing Representatives: Peter Kabemba and Monicah Murrey*

*Gus Egan and Jessica Novel provide essential and exceptional administrative support to the Commission always completing operational activities at the highest level of perfection with grace and kindness.*

Over 2022, the Commission members focused on key areas that chapter members had highlighted as important to them following a survey, namely access to educational programs.

#### **EASTERN MEDITERRANEAN AND AFRICA WEBINARS**

In collaboration between the Eastern Mediterranean and African regions, monthly webinars have continued to run on a Tuesday in French and on a Friday in English. Over 2022, the Eastern Mediterranean and African regions agreed to adapt the format to a focused single presentation, supported by a moderator and a wider panel. The presenters and moderators are from either region and alternate each month. This was to enable space for the often energetic and extensive questions that key topics generate. Presenters were encouraged to be from the local region, but the panel could be as diverse and geographically represented as would be helpful to optimize the theme. Over the year almost 3,300 delegates have attended the sessions live, and many more have downloaded the recorded open access sessions. Registrations extended well beyond the North African and African region, although members from these regions predominated. Despite face-to-face sessions becoming more viable, chapter members remain enthusiastic about this resource and as such it will continue as a most beneficial collaboration with the North African region. Most population themes were epileptic spasms (which was an interactive session allowing audience participation in French and English), status epilepticus, EEG and coma, movement disorders and epilepsy, prise en charge médicamenteuse des épilepsies de l'enfant (drug management of childhood epilepsies), developmental and epileptic encephalopathies, apport de la génétique dans le diagnostic des

epilepsies (contribution of genetics in the diagnosis of epilepsies) and neonatal seizures. In 2023, the program continues building on the popular and high demand topics. Thanks to Edward Kija, Vivian Ssonko and more recently Sam Gwer for facilitating the English-speaking webinars, and to Dominique Enyama, Constant Adjien, Zeinab Kone and more recently Moustapha N'diaye for facilitating the French-speaking webinars. Thanks as well to our colleagues from Northern Africa who share this collaboration with African Region so well.

## EPISKILLS:

In lieu of the African Epilepsy Congress which would have been due to occur in 2021, the Commission agreed to run a series of theme focused longer webinars over each quarter. The sessions were named EpiSkills.

**EpiSkills 1: Applying the epilepsy syndrome classifications and updates on new treatment guidelines. 15 March 2022.** Session was coordinated by Dr Edward Kija.

- Updates on Epilepsy Syndrome Classifications (J. Helen Cross)
- Updates on Treatment Guidelines on Epilepsy (Melody Asukile)
- Updates on Treatment of Status Epilepticus (Jo Wilmschurst)

These were all highly topics and clinically relevant themes with recent and important updates that the membership was keen to hear.

**EpiSkills 2: Research Insights: Everything you need to know. 7 June 2022.**

- Status of research in Epilepsy in Africa overview (Pauline Samia)
- Setting up a successful research program – lessons and guidelines (Charles Newton)
- Developing high level basic science research in clinically relevant areas (e.g. Neurocysticercosis) (Joseph Raimondo)
- Managing large epidemiological and implementation science research using Nodding syndrome as an example (Richard Idro)
- Key things to consider when writing a research paper (Michael Sperling, *Epilepsia*)



**ILAE IBE AFRICA**

**EpiSkills Africa 2022**  
Session 1 of 4

**Applying the Epilepsy Syndrome Classifications & Updates on New Treatment Guidelines**

15 March, 5-7pm GMT, 6-8pm WAT  
7-9pm CAT, 8-10pm EAT  
Free Registration By Zoom

[www.ilae.org/congresses/webinars](http://www.ilae.org/congresses/webinars)



**ILAE IBE AFRICA**

**EpiSkills Africa 2022**  
Session 2 of 4

**Research Insights: Everything You Need to Know**

**7 June 2022**  
5-7:30pm GMT, 6-8:30pm WAT  
7-9:30pm CAT, 8-10:30pm EAT

**Status of research in Epilepsy in Africa overview**  
Dr. Pauline Samia (Kenya)

**Setting up a successful research program lessons and guidelines**  
Prof. Charles Newton (Tanzania)

**Developing high level basic science research in clinically relevant areas (eg Neurocysticercosis)**  
Dr. Joseph Raimondo (South Africa)

**Managing large epidemiological & implementation science research using Nodding Syndrome as an example**  
Dr. Richard Idro (Uganda)

**Key things to consider when writing a research paper**  
Dr. Mike Sperling (USA)  
Co-Editor *Epilepsia* Journal

**Panelist:** Dr. Vivian Ssonko Namale

**Panelist:** Dr. Richard Burman

**Panelist:** Prof. Jo Wilmschurst

**Panelist:** Dr. Alina Estherhuizen

Free registration by Zoom  
[ilae.org/congresses/webinars](http://ilae.org/congresses/webinars)

We reached some 14 African countries despite, as Naluca warned, competing with a major Zambian football match! The introduction by Pauline setting the scene of where we are with research on epilepsy in Africa – the good, the bad and the ugly, was followed by Charles’s eloquent overview of how to do research well, but in such a grounded way, laying out how hard it can be (save your data, clean it regularly, be pedantic!). Then Joe’s talk about basic science really blew us away – as Richard Burman says that he does all this incredible work in Africa and focused on work that translates to better care for people with epilepsy, is so impressive. This lead beautifully into Richard Idro’s talk in Nodding syndrome and we learnt so much about the disease itself but also the challenges and ways to do this type of research in restricted settings. The close of the session with Mike taking us through a wonderfully clear and pragmatic approach to getting research published with a focus on *Epilepsia*, was a perfect way to close the session. The panelists led by organiser Vivian, with support from Alina and Richard were such a good balance to generate discussion and constructive comments from the presentations.

### **Eskills 3: Education Training. 3 September 2022.**

Moderators: Zeinab Kone and Augustina Charway

This session was separated into 3 themes:

1. Access to clinical skills training – ideally in Africa for Africa (panel: Jo, Lawrence, and Gallo)
  - a. The WFN accredited training hubs in Africa (Gallo Diop)
  - b. Introduction to the African Paediatric Fellowship Program (Jo Wilmshurst)
  - c. Paediatric Epilepsy Training courses (Edward Kija)
2. Access to EEG training (panel: Melody, Lawrence, Jo and Veena)
  - a. Get Smarter online EEG course (Melody Asukile)
  - b. Access to paediatric EEG training in Africa (Veena Kander)
3. ILAE Academy (panel: Ingmar and Gagandeep)
  - a. Showcase of the academy resources (Ingmar Blümcke)
  - b. Primary healthcare workers epilepsy curriculum (Gagandeep Singh)



**ILAE IBE AFRICA**  
**EpiSkills Africa 2022**  
 Session 3 of 4  
**Education & Training**  
**6 September 2022**  
 5-7:30pm GMT, 6-8:30pm WAT  
 7-9:30pm CAT, 8-10:30pm EAT

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**Access to Clinical Skills Training**

**WFN Accredited Training Hubs in Africa**  
 Amadou Gallo Diop

**Introduction to the African Paediatric Fellowship Program**  
 Jo Wilmshurst

**Paediatric Epilepsy Training Courses**  
 Edward Kija

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**Access to EEG Training**

**NASA/UCT/WFN EEGonline Programme**  
 Melody Asukile

**Access to Paediatric EEG Training in Africa**  
 Veena Kander

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**ILAE Academy**

**Showcase of the Academy Resources**  
 Ingmar Blümcke

**Primary Healthcare Workers Epilepsy Curriculum**  
 Gagandeep Singh

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**Moderator**  
 Zeinab Koné

**Panellist**  
 Lawrence Tucker

**Free registration by Zoom**

#### **EpiSkills 4: Advocacy. 6 Dec 2022.**

The session was coordinated by Naluca Mwendaweli and moderated by Action Amos.

Speakers:

- Fred Beuchi – Epilepsy Awareness Advocate. Fred gave an inspiring presentation on the incredible and innovative activities he has undertaken and is still undertaking to bring epilepsy into the light and raise awareness.
- Abraham Ntshalintshali from the Eswatini Epilepsy Organisation presented the challenges faced by people with epilepsy in his country and the inspiring work he has been involved in with Action Amos (IBE Africa chair) as one of the countries IGAP implementation projects.
- Angelina Kalkooza – paediatric neurologist from Uganda presented sensitively and powerfully on issues around stigma affecting people with epilepsy.

**ILAE** **IBE** AFRICA

#### **EpiSkills Africa 2022 Session 4 of 4**

#### **Advocacy 6 December 2022**

Frederick Beuchi, Epilepsy Awareness Activist (Kenya)  
Abraham Ntshalintshali, Eswatini Epilepsy Org'n  
Dr. Angelina Kalkooza, Neurologist (Uganda)

5-7:30pm GMT, 6-8:30pm WAT  
7-9:30pm CAT, 8-10:30pm EAT  
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### **PAEDIATRIC EPILEPSY TRAINING COURSES**

The roll-out of the one-day Paediatric Epilepsy Training (PET) courses across Africa since 2016 has enabled entry level approaches for health care practitioners to be equipped with the skills and common language used in the management of epilepsy in children. The teaching, through the established faculties in South Africa, Kenya, Ghana, Uganda, and Tanzania, have continued to run on-line and face to face courses with the support of the BPNA. Over 2022 planning has been underway for the roll-out in 2023 of faculties for Zambia and Zimbabwe. Plus, the course is being translated into French and members from the French speaking countries have been assisting with the translation and back translation of the course. In addition, colleagues from Brazil provided an online course in November for healthcare practitioners in Angola and Mozambique, following highly successful previous courses. The demand for the courses only grows and the potential to adapt the template for adult epilepsy care is under exploration within the broader ILAE networks and would be of great interest to adult neurologists in Africa.

### **SUPPORT OF TRAINING COURSES**

The African Commission supplemented the VIREPA course with \$5,000 to increase the capacity to accept colleagues from African low- and middle-income countries at reduced rates. This resulted in three African applicants being able to attend courses. A similar process will occur for the ILAE Academy. Funds have been ring-fenced as well to support an African adult neurologist from Zambia to attend a highly rated neuropsychology course early in 2023. In 2022, the San Servolo course was also supported which permitted funding support towards the cost of one African attendee. Collaboration with the International Brain Research Organization has resulted in a successful grant award to support a school in 2023 which will be held in Cape Town in July with bursaries to support early career neuroscience clinicians. The theme will focus on the Intersectoral Global Action Plan for Epilepsy and other Neurological Disorders (IGAP). It is hoped that this collaboration will continue for two further cycles with similar schools in 2024



and 2025 if other parts of Africa. The 2023, school will immediately precede the Society of Neuroscientists of Africa (SONA) conference in Johannesburg.

## **REGIONAL COURSES**

A call early in 2022 resulted in the highest number of proposals for seed funding to support regional educational meetings. The standard was exceptionally high. Two were awarded immediately (Zambia and Benin) and following motivation to the ILAE executive committee, additional funding was re-purposed to support another three educational projects in Rwanda, Cameroon, and Nigeria. Reports from these meetings are being posted on the Africa Commission webpage.

## **THE GLOBAL HEALTH DATABASE**

This resource identifies research activities ongoing in different regions and enables contact points for potential funds and further collaborations. As such, each region indicates the research that is planned or is ongoing and keep this updated. The Africa region currently has 36 entries. Four or five of those are across more than one region. Naluca and Edward with the support of Ernest are coordinating keeping the Africa region up to date. It is impressive how many of the on-going project align so well with the implementation of the IGAP.

## **INTERSECTORAL GLOBAL ACTION PLAN FOR EPILEPSY AND OTHER NEUROLOGICAL DISORDERS**

As stated above, many of the activities within the Africa Commission align with the goals of the IGAP. The targeted implications were further addressed during the most recent Africa Commission chapter Townhall. This was held in Accra, Ghana, sandwiched between the WHO launch of the IGAP in Africa and the EpInA project workshop week. The Townhall was live online and had the following content:

- Introduction to IGAP (J. Helen Cross)
- IGAP relevance to access to care (Tina)
- IGAP relevance to education and training (Jo)
- IGAP relevance for advocacy and stigma (Angelina)

There was open commentary from the attending membership.

In 2023, promotion of and support for activities aligned to the IGAP will continue.

## **ACCOMPLISHMENTS**

Despite most of the work remaining online, the Commission has managed to generate some highly effective programs from the webinars, EpiSkills, supporting educational projects, and promoting roll-out of the IGAP. The Commission members are well-represented and each developing critical roles to ensure success in these areas. Townhall in Accra, between the WHO launch of the IGAP in Africa and the EpInA project workshop week focused on IGAP.

## HIGHLIGHTS

- The first English webinar of 2022 covered the topic of neonatal seizures – the interest and discussions from this continued for over an hour with some 300 questions. The huge demand for this topic alone illustrates the energy and interest in the African and Northern African region.
- The last EpiSkills session of the year focused on advocacy – it relayed some incredibly powerful messages and strengthened the Commission’s work with IBE.
- The quality of the education course proposals in 2022 was an illustration of the evolution and in practice in the region and how ready the Commission is to support IGAP related activities.

## RESEARCH AND PUBLISHED ARTICLES

Samia P, Hassell J, Hudson J, Ahmed A, Shah J, Hammond C, Kija E, Auvin S, Wilmshurst J  
Epilepsy research in Africa: A scoping review by the ILAE Pediatric Commission Research  
Advocacy Task Force. *Epilepsia*. 2022 Sep;63(9):2225-2241.

## MEETINGS

Online meetings occurred 6 times over the year and formal face-to -face Commission meeting with the Townhall occurred September in Accra, Ghana, 7 times in total.

*Report submitted by Jo Wilmshurst*