

# Report on the Symposium on Epilepsy in Children in UGANDA, September 2018.



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## **1.0 Background:**

Africa bears the impact of carrying the burden of the highest incidence and prevalence of active epilepsy compared to that of all other continents. An impressive number of individuals grappling with this disease in Africa reside in the rural areas, where the burden of disease is magnified by the high incidence of acquired causes, low community awareness, lack of basic infrastructure for adequate management and the large treatment gap.

One of the key challenges in the delivery of services to people with this disease in Africa is the setback of identifying, managing, and monitoring cases at the primary care level where a limited or non-existent human resource or infrastructure capacity prevails. Furthermore, the secondary or specialized level of care is often non-existent or highly concentrated in the urban centers.

Therefore to mitigate some of these issues, the International League Against Epilepsy Africa (ILAE-Africa) for the term 2017-2021 has as its goals to:

- i. Promote Epilepsy Awareness.
- ii. Improve Access to Epilepsy Care.
- iii. Conduct training in epilepsy and strengthen the education activities of ILAE-Africa.
- iv. Foster Epilepsy Research in the Region.
- v. Multiply ILAE membership in the region.

The Epilepsy Society Uganda (EPISOU), a branch of ILAE-Africa has the goal of **“Better care for epilepsy patients in Uganda”**, with a vision **“to have a country with controlled and well managed epilepsy”** and a mission **“to**

**ensure holistic care to patients with epilepsy by advocacy for drugs availability, capacity building and research”.**

In response to upholding the ILAE-Africa strategy, EPISOU held a joint Symposium on EPILEPSY IN CHILDREN, together with the UGANDA MEDICAL ASSOCIATION (U.M.A.) – ELGON REGION BRANCH and the UGANDA PAEDIATRIC ASSOCIATION (UPA) in a rural town in the eastern region of Uganda.

**Symposium Objectives:**

- 1) To raise awareness in the public with a view to create an atmosphere for prevention, early detection/diagnosis, effective treatment, and reduction of stigmatization and discrimination of people with epilepsy (PWE).
- 2) To update and improve the knowledge and ability among health professionals, and motivate and equip them, to give better preventive interventions, and care, for people with epilepsy.
- 3) To build and/or improve strategies, for better prevention of, and care for people with and/or affected by, epilepsy in the sub-region.

## 2.0 Details of the Symposium:

**Date:** 20<sup>th</sup>-21<sup>st</sup> September 2018

### **Location:**

Rock Classic Hotel, Tororo town –Eastern Uganda.



### **Time and Programme:**

The symposium was held from 8.00am -4.00pm, on both days and included prior radio talks shows to the general public on East FM and Rock Mambo FM radio stations regarding several issues on Epilepsy including its causes, care and coping with the stigma, delivered in the local languages. For the full detailed programme a copy is available at the end of this report.

### **Attendance:**

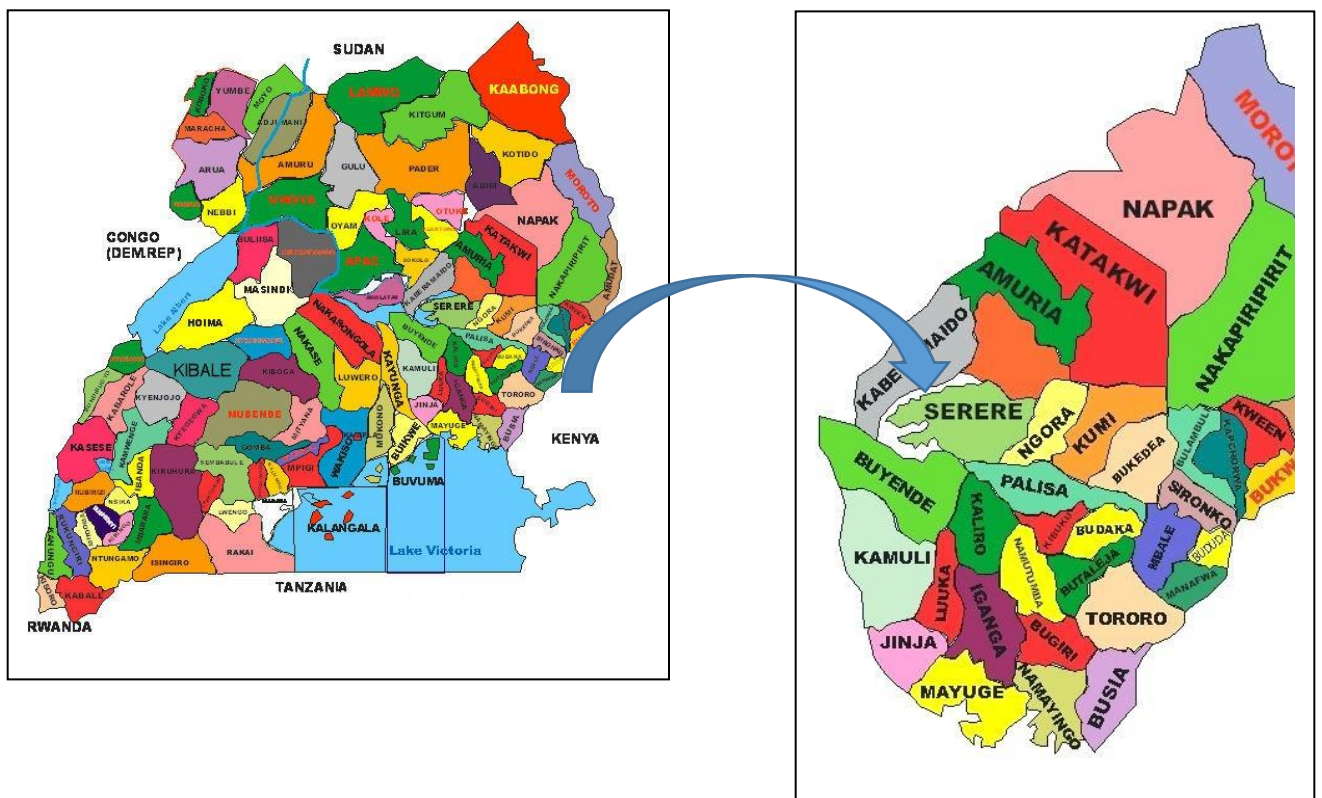
The target group were:

- 1) The General Community or Public.
- 2) The Affected Community including PWE, Parents, and Care-givers.
- 3) The Caring Community including Health Care Professionals and Supporting Partners.

The total number of attendees registered on Day 1 of the symposium was 83 out of an expected 100, and 61 out of an expected 80 for Day 2.

These included participants from the regional districts of Tororo, Busia, Butaleja, Pallisa, Mbale, Kween, and Kapchorwa.

**Figure 1:** Map Showing the Eastern Uganda Districts:



### **3.0 Summary of the Symposium:**

The symposium began with registration of the participants followed by welcome remarks from the district authorities as well as the representative from the district health services in Tororo district.

All the presenters (facilitators) as indicated on the program turned up in time and all the planned topics were covered.

On day 1, a pretest was done prior to the presentations and a post test at the end of the day. The mean score for the pre-test was 50.6% and post-test was 74.6%, indicating that the training had benefited the participants.

On Day 2, during the session **Joining Hands Against Epilepsy**, the empowered participants resolved to form **a regional forum or association** whose membership will include not only the people with epilepsy but also their care givers, health professionals, teachers and/or educators, administrators, and almost any other persons affected by epilepsy – to address the needs and challenges posed by epilepsy in the region and beyond. This promises to be a **powerful morally therapeutic and inspiring fellowship, as well as a lobby and/or advocacy platform for Persons Affected by Epilepsy (PAE)**. We hope that in future ILAE-Africa, PLAN (U), Tororo Cement, Uganda and World Vision, Uganda who were major contributors to this symposium will continue be part of, and support, this initiative.

## 4.0 Photo Gallery



District  
Authority  
making some  
opening  
remarks at  
the  
symposium





Symposium  
attendees  
DAY 1



Symposium  
attendees  
DAY 2



Some of the Symposia speakers giving their talks



Some of the caregivers with children having epilepsy sharing their story



The Radio Talk Show  
facilitators on the  
topics related to  
Epilepsy

**PROGRAMME FOR THE SYMPOSIUM ON EPILEPSY IN CHILDREN  
HELD AT THE ROCK CLASSIC HOTEL TORORO TOWN, UGANDA.  
20<sup>TH</sup>- 21<sup>ST</sup> SEPTEMBER 2019**

**ORGANIZED BY UMA ELGON REGION IN CONJUNCTION WITH  
UGANDA PEDIATRIC ASSOCIATION & SUPPORTING PARTNERS**

**For Health Professionals, People With Epilepsy, & Care Givers**

- I) **LOCAL FM RADIO TALK SHOWS** 10<sup>th</sup> – 20<sup>th</sup> Sept 2018.
- II) **SYMPOSIUM DAY 1: THURSDAY** 20<sup>TH</sup> SEPT 2018

<b>TIME</b>	<b>SESSION/TOPIC</b>	<b>CHAIR</b>	<b>LEAD PRESENTER &amp; ORGANIZATION</b>
08.00-8.30	Registration	<b>UMA ELGON E.C.</b> Dr.Joan O.Wamuluga	UMA Elgon Exctive Committee
08.30-8.40	Prayer & Welcome Remarks	MC: Dr.M.Mulongo	Chair-UMA Elgon,

8.40-50 8.50-9.	Remarks from UMA President Remarks from Host DHO	Co-MC :Dr.Julian Abeso	Dr.E.A. Obuku Dr.David C.Okumu.
	<b>DEFINITION,CLASSIFICATION&amp;DIAGNOSIS</b>		
09.00-9.30	<b>Seizures and Epilepsy:</b> Definition, Burden, Etiology, and Classification	<b>Conference Chair – Dr. Charles Engoru.</b>	Dr. Angelina Kakooza
09.30-10.00	<b>Diagnosis of Epilepsy:</b> History and Investigations	Do	Dr. Vincent Kayina
10.00-10.15	<b>Febrile Convulsions</b>		Dr.Shema Christine
10.15-10.45	<b>Epilepsy Syndromes:</b> A brief look at the common syndromes		Dr.Martin Chebet
10.45-11.15	<b>TEA/COFFEE BREAK</b>		
	<b>MANAGEMENT</b>		
11.15-11.30	<b>The Role of Imaging in Epilepsy</b>	Do	Dr. Elijah Wakamuke MRRH

11.30-12.00	<b>Principles of Management of Epilepsy</b>	Do	Dr.Richard Idro
12.00-12.30	<b>Acute Scenarios in Epilepsy</b>	Do	Dr. Martin Chebet
12.30-01.00	<b>Co-morbidities, Risks and Non-Drug Management of Epilepsy</b>	Do	Dr.Shema Christine
01.15	<b>OFFICIAL OPENING</b>		LC V Chair Tororo District
01.15-02.00	<b>LUNCH BREAK</b>		
	<b>LOCAL EXPERIENCES,CHALLENGES, &amp; CARE STRATEGY</b>	<b>Co-Chair</b>	
02.00-02.30	<b>Neurosurgical Aspects of Epilepsy:</b> The role of neurosurgery and long term outcomes		Dr.JustinOnen CURE, Mbale
02.30-03.00	Local Regional Research Findings & Experience (including SEEDS)	UPA/DHO/MS Tororo GH	Dr.Angelina Kakooza
03.00-03.30	Local Up-Country Experience with Epilepsy Care:		Sarah Mukite Psychiatry NO TGH

			Brenda Ndolera- Psychiatry NO- HCIV
03.30- 04.00	<b>Organizing Epilepsy Care:</b> Challenges and Way Forward	UMA/Elgon/DHOs	Dr.Vincent Kayina /UMA/DHOs
04.00	Tea & Departure		
07.00- 08.00	FM Radio Talk Show		UPA/UMA/DHO

### III) SYMPOSIUM DAY 2: FRIDAY 21<sup>ST</sup> SEPT 2018

Time	Session/Topic	Chair/Moderator	Lead Presenter(s) & Organizer
8.00- 9.00	Registration	UMA/DHOs	
9.00- 9.30	Prayer & Welcome Remarks		

9.30-10.30	<b>ABC of Epilepsy</b>		Dr. Angelina Kakooza
10.30-11.30	Experience of PWE & Care Givers		From Elgon.
11.30-12.00	<b>TEA/COFFEE BREAK</b>		
12.00-01.00	Experience of CHW with Epilepsy Care		From Tororo
01.00-01.30	Recommendations for Prevention, Early Diagnosis and Better Care		UPA /UMA Elgon
01.30	<b>LUNCHEON</b>		RDC, MOH.
02.30-03.30	Interactive Session-Challenges of Epilepsy Case Management in resource limited settings-(Case scenarios with open discussion)		Dr. Idro Richard & UPA Team
03.30-04.00	Joining Hands Against Epilepsy: Launch of Eastern Region- Local Branch of Epilepsy Society Uganda.		ELGON TEAM
04.00	OFFICIAL CLOSURE followed by Tea & Departure		RDC, MOH.