EPILEPSY SUPPORT ASSOCIATION UGANDA

A REPORT ON EPILEPSY NATIONAL ADVOCACY CONFERENCE

HELD ON THE 7TH DECEMBER 2012 AT GRAND IMPERIAL HOTEL KAMPALA

Report by Ocoto William

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LIST OF ACRONYMS

AED's	**Anti Epileptic Drugs**
BOD:	**Board of Directors**
COUL	**Creative Options Uganda Limited**
CRPD	**Convention on the Rights of Persons with Disabilities**
CSO	**Civil Society Organisation**
DEA	**Banish Epilepsy Association**
DPOD	**Disabled People's Organisation Denmark**
ESAU	**Epilepsy Support Association**
HMIS	**Health Management Information System**
IBE	**International Bureau of Epilepsy**
IEC	**Information Education and Communication**
MoU	**Memorandum of Understanding**
MSRHR	**Maternal Health Sexual Reproductive Health and Rights**
NGO	**Non-Governmental Organisation**
NMS	**National Medical Stores**
NUDIPU	**National Union of Disabled Persons of Uganda**
NUWODU	**National Union of Women with Disabilities of Uganda**
PCOs	**Psychiatric Clinical Officers**
PPC	**Principal Psychiatric Clinical Officers**
PWD	**People with Disabilities**
PWE	**People with Epilepsy**
UBOS	**Uganda Bureau of Statistics**
USDC	**Uganda Society for Disabled Children**
SRHR	**Sexual Reproductive Health and Rights**
WHO	**World Health Organisation**
VHR	**Voices on Health Rights**

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1.0 INTRODUCTION

Epilepsy Support Association Uganda (ESAU) is a local non governmental Organization that brings together persons with epilepsy and other people with the main aim of creating a better understanding of epilepsy and those who live with it. ESAU has branches at the district and Sub county levels and all have committees that spear head them.

As a way of advocating for people with epilepsy, Epilepsy Support Association Uganda organized a one day Epilepsy National Advocacy conference on the 7th/Dec/2012 at Grand Imperial Hotel Kampala. This conference brought together the officials from the ministry of Health, Medical professionals, ESAU partners and district branch leaders etc.

1.1 Objectives of the conference

- To create a national forum through which issues related to epilepsy will be discussed and common action agreed upon.
- To bring together users, professionals, policy makers and other service providers so they can share experiences related to their work and explore avenues for future collaboration and networking.
- To advocate for epilepsy as an emerging yet neglected public health concern in Uganda.
- Share current epilepsy research findings on treatment, management and prevalence

1.2 Over view of ESAU

ESAU National Director made an overview of ESAU to the participants and a number of issues were discussed. Major emphasis was on the following

- Mission
- Vision
- Objectives
- Goal
- Principles and Core values
- Causes of Epilepsy
- First aid and management
- Drug bank
- Focus for the future

1.3 Welcome Remarks

ESAU BOD chairman gave a brief welcome remark and in his speech, he introduced himself on behalf of the BOD members and welcomed every body to the conference. He however noticed that, the major problem facing people with epilepsy is stigmatization. The chairman also told participants that ESAU currently has a membership of 10,000 members and has branches in 36 districts. He thanked the government for providing essential medication for people with epilepsy. He then finally thanked ESAU partners for the good working relationship.

1.4 Official Opening

The conference began at 9:30am with the introduction of members in attendance followed by the opening remarks by the official from the ministry of Health who welcomed participants and thanked ESAU for offering social support to people with epilepsy where she said ministry of health is committed in working together with ESAU in order to address the plight of people living with epilepsy. She then declared the conference officially opened.

2.0 Epilepsy and Mental Health

The official from the ministry of health who presented this topic informed participants that mental health is a state of well being in which the individual realizes his or her abilities where she noted that under mental health, Depression alone accounts for 4.3% of global disease burden and it is among the largest single cause of disabilities. She then told participants that, there is a relationship between mental illnesses and Epilepsy. The presenter also told participants that Epilepsy has been included in the clinical guidelines and several medicines put in the essential medication list and anti epileptic medicine are being centrally procured by National Medical Stores.

The manual for the in service training of health professionals has been made including epilepsy however she also told participants that, there is actually inadequate research carried out on epilepsy and people with epilepsy are still being stigmatized but she pledged that the ministry of health will ensure the education of the public about Epilepsy.

3.0 Epilepsy Prevalence in 4 selected Districts of Uganda

A presentation on the prevalence of epilepsy in 4 selected districts was given by Dr Joyce Kaducu a lecturer and a PHD student of Gulu University who carried out a research to ascertain the prevalence of epilepsy in the districts of Moyo, Adjumani, Kitgum and Gulu. She began by saying that 50 million people in the world have epilepsy and 80% of them are in developing countries like Uganda.

3.1 What Causes Epilepsy?

In her presentation, she told participants that, in about 70% of people with epilepsy, the cause is not known and in 30%, most common causes are:

- Head trauma
- Infection of brain tissue
- Brain tumor and stroke
- Heredity
- Prenatal disturbance of brain development
- Structural damage to the brain

The Epilepsy prevalence rate below the age of 18 in the 4 selected districts is as illustrated below

S/NO	District	Percentage (%)
1	Kitgum	2.7
2	Gulu	2.2
3	Adjumani	1.7
4	Moyo	1.6

3.2 Results - prevalence

- During the study period, 42,903 people were screened.
- One thousand three hundred and eighty three (1,383) people had epileptic seizures.
- Overall prevalence of epileptic seizures was found to be 32 per a thousand in Northern Uganda.
- Majority of the patients 772 (55.8%) patients were male.

She also told participants that during her study, a total of 60 patients underwent brain CT-scan. Forty one (38.7%) patients had abnormal brain CT-scan findings.

She said her finding also reveals that the major challenges faced by people with epilepsy are:-

- Social stigma
- Poor attitude
- Traditional healers
- Lack of resources
- Ignorance
- Discrimination in education
- Low priority
- Inadequate supply of anti epileptic drugs (AED's)
- Poor drug compliance
- Inadequate training of medical personnel
- High rate of refractory frequent brain damage

In her recommendations she emphasized the following:-

- Training all cadres of health workers
- Massive media campaign
- Integrating epilepsy in primary health care
- Collaboration with other government sectors

In her conclusion, she said that, the study got high prevalence rate of an average of 3.4% per district of study with prenatal brain damage being the major cause.

4.0 Epilepsy and the Nodding syndrome

Official from the nodding disease taskforce in the name of Dr Bernard Opar Toliva gave a presentation about epilepsy and the Nodding syndrome where he said that, Nodding syndrome is a complex type of epilepsy that is characterized by repeated head nodding that occurs from 5-20 times per minutes. It occurs across the age distribution of 5-17 years. Voluntary head nodding is not nodding syndrome.

In his presentation, he informed participant that, in August 2009, a study conducted in the districts of Kitgum, pader and Lamwo confirmed a new condition of epilepsy like and the same study also revealed that, this condition started in 2003 from Internally Displaced People's Camps (IDP's) and predominantly well spread through the age groups of 5-15 years old. Parasitic infections were thought to be a cause-esp. Cysticercosis, Toxoplasmosis, Schistosomiasis, Trypanosomiasis etc

Following the revelation of this new condition, the Ministry of Health came out with the following actions:-

- ❖ Developed a comprehensive response plan
- ❖ Formed a National Task Force
- ❖ Formed a Research sub Committee
- ❖ Created a core team for case management that developed a training manual for case management
- ❖ Trained health workers
- ❖ Opened treatment centers- initially in 3 districts, but this has since been expanded to 7 districts
- ❖ Conducted a preliminary epidemiological survey together with partners- CDC, WHO, AFENET, MUSPH, findings are in the next slide
- ❖ Spot maps -Nodding syndrome
- ❖ Spot map epilepsy
- ❖ Comparison

The cases of nodding syndrome reported from the time of it's revelation up 7th/Dec/2012 are as indicated in the table

S/NO	District	Number
1	Kitgum	1,084
2	Pader	1,982
3	Lamwo	479
	Total	**3,545**

During the same period, the number of people who have been reported to be having epilepsy was 7,037 so the total number of people with nodding syndrome and those with epilepsy as per 7th/ Dec/2012 was 10,582.

The presenter informed participants that as a way of combating nodding syndrome in the above districts, the government has embarked on aerial spraying of the banks of river Aswa where onchocerciasis shrives. He told participants that the condition is under control and the children who were put on medication are tremendously responding to treatment and there are no new cases reported in the recent past

5:0 Bringing up a child with Epilepsy.
A parent by the names Adiko Yayeri gave a live testimony of bringing up a child with epilepsy where she told participants that her daughter got epilepsy when she was 8 years old and in primary 3.

Challenges she faced:-

- At first, she was extremely Scared what disease has struck her child
- She did not understanding how to go about it.
- Advice from different people
- Association with peer, teachers, family members,
- Relatives, neighbors even when you are walking on the road.
- Medication where at the beginning when her daughter was fed up of the medicines she could throw them away.
- Deceive her that she has swallowed her medicine but goes to spit it out.
- Costs of the medicines are not easily affordable for her
- Changing of medicines was at times a problem because it would bring difficult symptoms.

She narrated the life styles of her daughter and she told participants that it is not easy to bring up a child with epilepsy because a child with epilepsy has some abnormal behavior compared to children who do not have epilepsy. She said she went to different doctors for medication but at first these medications were not working until one time when she was put on sodium valprate. She thanked ESAU for supporting her daughter in terms of Psycho social support

6:0 Patients Rights (Especially those with Chronic Diseases)
The Director CHAIN Ms. Regina Kamoga gave a presentation about patient rights and she started by saying that, CHAIN is an umbrella Organization of people with chronic conditions and so it is a patient organization. She said that originally patients were seen as passive recipients of services. She said patient centered health care is the way to go because patients who know their rights are active participants. She said among the rights and responsibilities of patients are the following:-

Rights

- Right to medical care
- Rights of receiving visitors
- Right to information
- Right to be treated by a named health care provider
- Right to chose and know who is treating them
- Right of refusal
- Right to be referred to a second option
- Right to a health and safe environment
- Right to continuity of care
- Rights to confidentiality and privacy
- Right to know drug interaction, storage and use including indicators dose and availability.

Responsibilities

- Provision of information i.e. should provide the right information to the doctors
- Seek medical care
- Adhere to medication
- Respect and consideration
- Respect and be respected
- Not to be confrontational

What prevents patients from exercising their rights?

- Fear
- Poverty
- Patient doctor ratio
- Low knowledge about our rights
- Depends on the type of pain
- In effective communication
- Attitude
- Ignorance about rights

She then said that, patients can be empowered by building their capacity, health literacy and she said an expert/empowered patient makes the work of the health worker easy.

7.0 Post Traumatic Epilepsy (Boda Bodas, road accident)

This topic was presented by Dr JB Mukasa from Mulago National Referral Hospital where he began his presentation by showing the pictures of vehicles which got involved in accidents. He said one of the causes of epilepsy especially in adult is accident which results into brain injuries. He said the mechanism of brain injuries includes:-

- Blunt injuries
- Heavy velocity penetrating objects
- Motor vehicles accident

The Doctor informed participants that accident is less in developed countries and more in developing countries for example he said this year alone Uganda has lost 3,000 people in road accidents due to:-

- Careless driving
- Poor roads
- Alcohol
- Over speeding
- Dangerous Mechanical Conditioned Vehicles (DMC)

The diagnoses of post traumatic epilepsy are:-

- Through history taking
- Neurological examinations
- Neurological imaging
- EEG

The management of post traumatic epilepsy among other includes:-

- Anti epileptic drugs
- Nerve stimulation
- Surgical resection of epilepsy
- Life style modification
- Counseling

Shortcomings in managing post traumatic epilepsy

- Lack of specialist
- Lack of equipment
- Expensive anti epileptic drugs

8.0 Closing Remarks

ESAU National Director on his concluding remarks told participants that it has been of great significance to bring you here for the whole day and talk about epilepsy where he appreciated ESAU partners and he wished participants safe journey back home and a merry Christmas to every body

EPILEPSY SUPPORT ASSOCIATION UGANDA

APPENDIX 1

NATIONAL EPILEPSY ADVOCACY CONFERENCE.

GRAND IMPERIAL HOTEL-KAMPALA

FRIDAY 07TH DECEMBER 2012

TIME	ACTIVITY	PRESENTER	SESSION CHAIR
08:30-09:00Am	Arrival and Registration the Participants	Clare, Paul & Sarah	
09:00-09:10Am	Objectives of the Conference	Justine	Dr.Sheila Ndyanabangi
09:10-09:30Am	Over view of ESAU	ESAU National Director	
09:30-09:45Am	Welcome Remarks	ESAU BOD Chairman	
09:45-10:00Am	Arrival of the Guest of Honor	Augustine	
10:30-10:20Am	Epilepsy and Mental Health	Dr.Sheila Ndyanabangi	
10:20-11:00Am	Official Opening Remarks	Guest of Honor	
11:00-11:30Am	**HEALTH BREAK**	**HOTEL**	
11:30-12:00Pm	**KEY NOTE ADDRESS** Epilepsy prevalence in 4 selected Districts of Uganda	Dr. Joyce Kaducu	Dr.Matovu Muwonge
12:00-12:30Pm	**KEY NOTE ADDRESS** Epilepsy and the Nodding disease	National Nodding Syndrome Task Force (Dr. Opar Bernard)	
12:30-01:00Pm	Open discussion and Reactions	Dr. Joyce Kaducu Dr. Opar Bernard	
01:00-02:00Pm	**LUNCH**	**HOTEL**	
02:00-02:30Pm	**KEY NOTE ADDRESS** Patients Rights	Ms. Regina Kamoga	Dr.Joseph Baguma And Mr. Jackson Chekekwo
02:30-03:00Pm	**KEY NOTE ADDRESS** Boda Bodas, road accidents and epilepsy	Dr. J.B Mukasa	
03:00-03:45Pm	Open discussion and Reactions	Dr. J.B Mukasa Ms. Regina Kamoga	
03:45-04:00Pm	Official Closing Remarks	Hon.Sulaiman K. Madada	
04:00-04:30Pm	Evening Tea	**HOTEL**	
04:30-05:00Pm	Administrative issues, Closure and Departure	Sarah	

APPENDIX 2

PRESENTATIONS

ABOUT ESAU
By: Agustine Mugarura

ABOUT ESAU
Epilepsy Support Association Uganda is an indigenous NGO that brings together people with epilepsy, their families and other people to work towards eliminating the social stigma attached to epilepsy and to create an environment in which epilepsy is better understood so that those who live with it can exercise their full potential and enjoy equal rights.

ABOUT ESAU
Established in 1997, the Association supports People With Epilepsy (PWE) to form support groups through which they can meet to share experiences, offer each other mutual support and lobby for better services at both sub county and district levels. The

ABOUT ESAU
The association is democratically governed by the members who elect a local executive committee at sub-county and district levels. Each district branch sends two delegates to a national assembly that elects a national board. At the helm of the association is the board which is the policy making organ of the association. The board is then responsible for recruiting the staff that runs the secretariat.

ABOUT ESAU
Mission
"To encourage and empower PWE in order to participate in developmental activities, be able to advocate for their rights and command respect in their entire communities that need to be sensitized"

Vision
A Ugandan society in which epilepsy is understood and PWE are treated with dignity so they can exercise their full potential and participate in all developmental processes.

OBJECTIVES

To build an association in which people with epilepsy and their relatives are empowered and participating in advocacy and lobbying for their rights to achieve dignity and equal opportunities.
To empower ESAU structures engage decision makers at the district and sub-county levels for effective service delivery.
To create awareness among PWE, their relatives, health workers, opinion leaders and the community so they understand epilepsy and are able to support PWE.
To build networks and alliances through which ESAU can advocate for the rights of PWE

WHAT WE DO
Providing information on epilepsy
Mobilising PWE to make associations and to join ESAU
Lobbying and advocating for PWE at national, subcounty and district levels.
Training both PWE and other stakeholders

Building the capacity of PWE to own and manage the organization efficiently
Fundraising for ESAU activities
Motivating PWE to consume services by running a Drug Bank
Referral

WHAT WE DO

FOCUS FOR THE FUTURE

Involvement of youth with epilepsy in ESAU activities
Strengthen Partnerships with service providers
Formation of School epilepsy clubs
More awareness in Schools & Institutions
Improve fundraising from corporate agencies
Advocacy focus on districts
Continue collaboration with professionals
Strengthen the drug bank initiative
Establish IGAs for PWE

CAUSES OF EPILEPSY

Un known causes
Hereditary causes
Birth injury
Febrile convulsions during childhood
Infections(Syphilis,HIV/Aids,tape worms,ochocerciasis)
Head injury
Brain tumors
Alcohol abuse
Measles
Meningitis
Drug abuse

NOTE: Witch craft, demons or curses do not cause epilepsy!!

FIRST AID

PROTECT THE HEAD

FIRST AID

LOOSEN
TIGHT
CLOTHINGS

FIRST AID

PUT THE PERSON IN A RECOVERY POSITION AND COVER HIM/HER

FIRST AID

GIVE CARE, LOVE AND RE ASSURE THE PERSON

FIRST AID

REFFER OR CALL A HEALTH FERCILITY
NEVER LIFT A PERSON IN AN ATTACK
NEVER GIVE ANYTHING TO EAT OR DRINK
NEVER GIVE MEDICATION DURING A SEIZURE

CHALLENGES OF PWE

Neuropsychological effects like: poor memory, language skills, executive functions and motor speed.

They are also prone to migraines, psychological problems especially anxiety and depression. People with Epilepsy (PWE) are approximately five times more likely to have psychiatric problems than the general population and the more the frequency of seizures the greater the degree of psychopathology.

Furthermore psychiatric disease is associated with suicide in PWE.

CHALLENGES OF PWE

PWE and their families are often stigmatised by society.

Misconceptions about the cause of epilepsy, mean that many are not accepted in some communities

These factors may influence decision to seek medical advice and treatment.

PWE are less likely to attend school, obtain a job or marry.

WHAT WE NEED TO DO

The public and the patients need to develop a positive attitude to seizure disorders in general, so as to minimise on the stigma attached to these conditions.

Sensitisation of the public in order to raise awareness through talk shows, the visual and printed media and schools should be encouraged.

Peer Support groups for patients with epilepsy should be strengthened

WHAT WE NEED TO DO

Epilepsy should receive healthcare priority in Schools and other learning Institutions.

Need to encourage parents, relatives, friends, public and private sectors and NGO's to get involved in the local activities of the Global Campaign against Epilepsy.

Elimination of discrimination against epilepsy in all spheres of life, particularly in schools and at work places.

WHAT WE NEED TO DO

Promote interaction with traditional health systems.

Listen to PWE and give them same treatment like other patients

Encourage basic and applied research on epilepsy.

Encourage regional and continental co -operation.

TOGETHER WE CAN BRING EPILEPSY IN UGANDA OUT OF THE SHADOWS

WELCOME REMARKS

By: Andrew Odongo

WELCOME REMARKS

On Behalf of the ESAU BOD, allow me to welcome you to this important workshop. The main challenges facing people with Epilepsy in Uganda is social stigma that originates from lack of information on Epilepsy. By organising this workshop, ESAU would wish to draw the attention of the Government of Uganda, policy makers, Professionals and the general public to the plight of People with Epilepsy.

For the last 15 years ESAU has laboured to create a better understanding of Epilepsy. We are so far in 36 districts and in 139 Sub counties where we have recruited 10,300 members. ESAU structures are composed of a sub county Executives comprised of 7 members who converge during an election to form a District General Assembly and a District Executive of 9 members in each district who meet 2 delegates of whom comprise the National General Assembly and elect a BOD that governs the activities of the Association.

I would like to take this opportunity to thank the Government of the Republic of Uganda for providing regular medication for persons with epilepsy at health centre III's and IV's through National Medical Stores. We hope this process will continue and that health centre three's will get more of these Anti Epileptic medication timely.

Epilepsy has categories / types; Medical Practitioners have written that Nodding Disease is a type of Epilepsy. I would like to encourage the Government of Uganda through their live Ministry, Ministry of Health to come out clearly and declare them on the Nodding Disease, so as an Association we are able to mobilise our members according to the Government declaration.

Government has continued to recruit personnel for mental Health in various health centre III's and IV's and we as an Association are grateful that all people with epilepsy can access treatment and medical attention from trained / skilled medical personnel. This has helped improve the welfare and dignity of people with epilepsy and they are participating in local initiatives and development programmes in their respective communities, hoping the process will continue. We thank the professionals working with persons with epilepsy for their diligent support to people with epilepsy.

ESAU would like to thank her donors, the Danish Epilepsy Association / DANIDA, the Swedish Development Agency, International Bureau foe Epilepsy for the financial support they have provided and enabled programmes of the Association to smoothly operate.

In the same vein I would like to thank ESAU partners who have come today for this national Advocacy Workshop and for the effort they have put into realising the dignity of people with epilepsy through inclusion of people with epilepsy in the and programmes. Special thanks go to the National Union of Disabled Persons, National Union of Women with Disabilities in Uganda, Disabled Persons, Organisations and member of International Alliance of Patients Organisation, and Voices of Health Rights members. We hope this spirit of networking and cooperation will continue in the same vein.

Present in this meeting are partners from Not for Profit Health Units / Faith Based Health Units in 56 health units where ESAU has established Community Drug Banks. We thank them for their encasement of the establishment of the establishment of these drug banks. We hope this cooperation shall continue as people with epilepsy through these partnerships have been provided with regular and affordable medication which is determined by their participation in development processes.

ESAU has branches in 36 Districts Local Governments structures and would like to appreciate the enasting environment created by the support of District Local Governments for People with Epilepsy. Special thanks go to District Local Governments of Masaka, Adjumani, Moyo, Kabale, Soroti, Jinja and Amuria for budgeting for People with Epilepsy through Government programmes like Special grant for People with Disabilities, Community Driven Development Programme, NUSAF among many others. We pray this cooperation continues for the benefit of persons living with epilepsy

CONCLUSION

We hope to continue with this work of Awareness raising on Epilepsy, Advocacy Counselling and referral of people with epilepsy. In the next two years, ESAU will focus on Northern Uganda in the districts of Amuru, Gulu, Kitgum and Pader with the same strategies of mobilising people with epilepsy through Forum Theatre.

I thank you all for this opportunity to interact with you. I thank all for coming and wish you safe journey back home

THANK

EPILEPSY PREVALENCE IN 4 SELECTED DISTRICTS

By: Dr Joyce Moriku Kaducu

Background

- Epilepsy is the most common serious brain disorder, affecting individuals in all age groups.
- A **Seizure** is a brief, temporary disturbance in the brain's electrical activity.
- **Epilepsy** is a medical condition characterized by recurrent seizures.
- While people with epilepsy have seizures, not everyone who has a seizure has epilepsy.

Burden of the Disease

- WHO estimates that 50 million P'ple are affected & more than 80% are found in the tropics.

  (Geneva, WHO 2001)
- The immense burden

  is a growing problem in
  developing countries where
  the incidence is higher than
  in developed countries
  (Sander JW, et al.1996; 61:433–43.)

Who Has Epilepsy

- Studies in Africa have shown that the prevalence of epilepsy ranges between 15 and 52 per thousand ***(Preux et al., 2000).***

- A study done in Rukungiri

District of Western Uganda found
age-specific prevalence of
epilepsy in children < 15 years
was 2.04 % based on 395 cases.
(Dunne E et al 2010)

Out –Patient report 2011 Gulu RRH

Out –Patient report 2012 Gulu RRH

Burden of the Disease ……….

- Epilepsy is one of the most common neurological disorder and has no age, racial, social, gender or geographical boundaries.

- Epilepsy can have profound

social, physical and
psychological
consequences.

- People with epilepsy

continually face social
stigma and exclusion.

The Brain Is the Source of Epilepsy

What Causes Epilepsy?

4.0 In about 70% of people with epilepsy, the cause is not known

5.0 In 30%, most common causes are:

- Head trauma
- Infection of brain tissue
- Brain tumor and stroke
- Heredity
- Prenatal disturbance of brain development
- Structural damage to the brain

What Happens During a Seizure

Generalized seizure
Involve the whole brain and loss of consciousness
Absence: characterized by brief loss of consciousness

Tonic-clonic: characterized by rhythmic jerking of muscles
Partial seizure
Involve only part of the brain; may or may not include loss of consciousness
Symptoms relate to the part of the brain affected

The Study in Four districts of Northern Uganda

Study Objectives

To establish the overall prevalence and factors associated with epilepsy/epileptic seizures in all age groups in Moyo, Adjumani, Kitgum and Gulu districts.

Study Methods

A cross sectional multistage cluster random survey using a screening questionnaire was administered to find suspected cases of epilepsy/epileptic seizures.

Study methods

An in-depth questionnaire was administered for confirmed cases with epilepsy

Study methods

Identified suspected cases were performed neurological examination by neurologists and as well for confirmation of the presence of epilepsy.

Study methods

Randomly selected people with epilepsy were subjected to brain CT-scan at KIC

Study methods

Randomly selected people with epilepsy were subjected to blood sample withdrawal for serology at KIC

Results - prevalence

- During the study period, 42,903 people were screened.

2.0 One thousand three hundred and eighty three (1,383) people had epileptic seizures.

3.0 Overall prevalence of epileptic seizures was found to be 32 per a thousand in Northern Uganda.

4.0 Majority of the patients 772 (55.8%) patients were male.

Results - prevalence

Results – prevalence

Results – Etiologic factors

A total of 60 patients underwent brain CT-scan. Forty one (38.7%) patients had abnormal brain CT-scan findings.

Results- etiologic factors

Results – etiologic factors

Neurocysticercosis

- Poor hygiene & living conditions, allowing pigs access to human faeces, put people at risk of developing cysticercosis.

- In humans, cysts form

  mainly in subcutaneous

tissue, skeletal muscle,
the eye and the nervous
system ***(Serpa et al. 2006).***

- Neurocysticercosis (NCC)

represents the commonest
helminthic disease of the
central nervous system
(Burneo & Garcia 2001, Del Brutto 2006).

Neurocysticercosis

Caused by *Taenia solium* and the most common cause of epilepsy in the developing countries ***(Garcia et al 2003; Prasad et al 2008b).***

Challenges in Epilepsy control.

High level of social stigma and negative prejudices.
Poor attitude and traditional beliefs .
Ignorance.
Discrimination in education.
Traditional healers. Most patients tend to consult them first.
Lack of resources. High poverty level.
Low priority

Challenges in Epilepsy control.

Inadequate supply of AEDs.
Poor drug compliance. Cost of drugs.
Inadequate training of Medical Personnel.
High rate of refractory seizures (30%) in children because of frequent brain damage, complex types of seizures and Syndromes.

Way forward

- Training all cadres of health personnel in epilepsy management
- To educate and empower various groups within the communities and their families.

Ways of creating awareness.

- Mass media campaigns.
- Oral presentations at public gatherings, churches, schools, institutions etc.
- Distribution of Educational and Information Material.

Way forward

- Integrating epilepsy into the primary health care system.
- Collaboration with other government sectors e.g. education, culture and social services
- Commitment of resources to epilepsy activities.
- Training of health workers to improve epilepsy management skills

- Health facility support – drugs

Conclusion
This study found a high prevalence of epilepsy in Northern Uganda.
There is some suggestion that neurocysticercosis may play a role.
Efforts should be made to development of a successful model of epilepsy control that will be integrated in the health care systems.
What Epilepsy is Not:
People with Epilepsy can …

Acknowledgement
Special thanks go to all patients with epilepsy who participated in this study.
Thanks to all patients with epilepsy & their caretakers
We are profoundly indebted to Germany Research Foundation (DFG) for funding this study.
Thanks to the leadership of Gulu, Kitgum, Moyo and Adjumani districts for the invaluable support accorded during data collection.
Epilepsy Support Association of Uganda

Everything you do,
you do with your brain!

EPILEPSY AND NODDING SYNDROME
By: Dr Opar Bernard Toliva

- National Coordinator- Nodding Syndrome National Response- Ministry of Health
- 7th December 2012
- INTRODUCTION
- Question
- Epilepsy and Nodding Syndrome: What is the difference ?
- **nodding Syndrome**
- A complex type of epilepsy
- Characterized by repeated head nodding
- Growth retardation in a previously normal growing child
- Aged between 3-18 yrs

- Associated with mental and cognitive function retardation
- Physical abnormalities especially of both upper and lower limbs, lip and dental abnormalities
- Drooling of saliva, and
- Malnutrition
- **Suspect**
- Reported head nodding* in a previously normal person

  *repetitive involuntary drops of the head towards the chest on 2 or more occasions
- **Probable case**
- Suspect case of head nodding, with

Both Major Criteria

- Age of onset of nodding between 3-18 yrs
- Frequency of nodding 5-20/minute

Plus at least one of the following Minor Criteria

- Neurological abnormalities (cognitive decline, school dropout due to cognitive / behavioral problems, other seizures or neurological abnormalities)
- Clustering in space or time with similar cases
- Triggering by food, cold weather
- Stunting or wasting
- Delayed sexual or physical development
- Psychiatric symptoms

- How do the cases look like?
- **What Is the current situation on nodding syndrome like?**

- In August 2009 reports from District Health Office of Kitgum District about a progressive disease characterized by head nodding , mental retardation and stunted growth was officially received by MOH
- A similar condition had been noticed in Pader and Lamwo districts as well

- Ministry of Health and partners- WHO, CDC, AFENET conducted a series of investigations that resulted into amongst other things, the following:

- cont

1. Confirmation of the existence of the strange condition
2. Characterization of the condition
3. Identification and mapping of the most affected areas
4. Estimation of the burden of the condition

- **Background information**

- It had been however been observed in surveys conducted by Nyomugenyi et al that there was an abnormally high prevalence of epilepsy in northern Uganda
- That the condition could have started as early as 2003 when most of the population was in IDP

- Cont

A vast number of theories have been advanced about the condition:

- It affected predominantly the age group of 5- 15 years
- It was thought to be a Progressive Cerebro- Musculo-Skeletal Epileptogenic Syndrome
- Parasitic infections were thought to be a cause- esp. Cysticercosis, Toxoplasmosis, Schistosomiasis, Trypanosomiasis etc

- cont

- Others thought it was congenital syphilis or metabolic or nutritional disorders or intoxicants- heavy metals, poisons or drugs
- Others thought it was associated with military munitions, and military ordinance contaminations, endocrine anomalies or autoimmune disorders
- However, to date most of these have been ruled out
- Only significant finding was Onchocerciasis antibodies

- Areas of focus
- **Actions by Ministry of health**
- Developed a comprehensive response plan

- Formed a National Task Force
- Formed a Research sub Committee
- Created a core team for case management that developed a training manual for case management
- Trained health workers
- Opened treatment centers- initially in 3 districts, but this has since been expanded to 7 districts
- Conducted a preliminary epidemiological survey together with partners- CDC, WHO, AFENET, MUSPH, findings are in the next slide
- Total Nodding Syndrome
- Spot maps -Nodding syndrome
- Spot map epilepsy
- Comparison
- Nodding syndrome
- Epilepsy
- What is the picture from the treatment centers
- Current status
- PRELIMINARY MINI CLINICAL AUDIT
- Richard Idro
- Opar Bernard Toliva

- **Clinical audit**

Aims:
a)Assess the feasibility of conducting a quick audit to assess treatment effects in outpatient patients during follow up clinic consultations.
b) Provide a preliminary overview of the impact of the Ministry of Health treatment interventions prior to a more definite evaluation.

- .

Main outcome measures for improvements were:

- · Seizure control
- · Improvements in nutritional status
- · Ability to independently perform activities of daily living and simple home care tasks
- · Schooling in school age children
- Results
- **Conclusion**
- Findings suggest that children with nodding syndrome and those with other epilepsies are improving with the Ministry of Health treatment interventions.
- Up to 2/3 of patients may be seizure free, over 3/4 may be requiring only minimal supervision in activities of daily living and about 1/3 may be back in school.
- cont
- Even in the absence of a known etiology, the Ministry of Health may be in the right direction in relieving morbidity and alleviating the suffering of the patients.
- However, a more comprehensive audit should be performed at least 1 year after the interventions.
- Weaknesses observed in this audit may be useful in improving the bigger audit.

- ACKNOWLEDGEMENT
- MOH NTF
- OPM
- PARTNERS- WHO, CDC, AFENET, MUSPH
- MEMBERS OF THE NATIONAL CORE TEAM ON CASE MANAGENET
- DR. WAMALA- SENIOR EPIDEMIOLOGIST – MOH
- DR. RICHARD IDRO – MULAGO HOSPITAL

- MAJOR QUESTION

ARE THESE FINDINGS TRUE ?

BRINGING UP A CHILD WITH EPILEPSY
By Yayeri Adiko

Challenges
At first, I was extremely Scared what disease has struck my child
Not understanding how to go about it.
Advice from different people
Association with peer, teachers, family members,
Relatives, neighbors even when you are walking on the road.
Medication
At the beginning when she is fed up of the medicines she throws them away.
Deceive that she has swallowed but goes to spit it out.
Costs of the medicines are not easily affordable
Changing of medicines was at times a problem because it would bring difficult symptoms.
Changing moods
Keep on changing.
Rude
Quiet no talking
Aggressive
Wants to eat what she wants
Can decide not to eat
Can decide to sit a lone
Abusive, she does not care who you are.
TV director, music DV play, All must listen
Academics
At the beginning before the on set of epilepsy,
Was doing so well and was always among the first ten pupils in class.
Third term in P.3 is when she started performing badly.
She became part of the children with mass hysteria in boarding school
From time to time, I had to withdraw her from school
Domestic chores
Does work as, and when she feels like.
Wants to do work without supervision
Should not correct, stop, or help her.
Should appreciate her, if you don't it becomes a big issue.
When visitors are at home, she wants them to pay attention to her stories.
She has very big dreams .
Behavior
She wants to be handled specially so she brags about it.
She loves visiting places and homes of friends but cannot finish even two days before she starts using undermining language on them.
She wants to be associated with the well to do and when gets that chance she turns around to abuse them
She fights other peoples wars.
Relationship with the opposite sex

She loves to be in the company of the opposite sex and no one should advice her b'se she knows all
She now likes the talk of boy and girl friend affairs.
She commands the boys she admires to obey her.
She uses the language that draws pity for her
My Dilema
I do not know how best I can handle the issue of boy girl relationship
Whenever I leave her with other people at home, I come back when she has pissed up everybody.
Cooks what she wants even when food is ready for all.
She sees me as a hindrance to her freedom.
THANK YOU

POSTTRAUMATIC EPILEPSY
By: Dr Mukasa JB.

- Defn &Mechanism of injury
- Blunt injury
- High velocity penetrating objects
- Motor vehicle accidents
- Epidemiology
- Less in developed countries
- More in developing contries
- Dr. Lugemwa's article of 3-11-2008= 1st accident in June,1922 on Masaka Rd
- This year >3000people dead
- Careless driving
- Reckless
- Over speeding
- Alcohol
- DMC vehicles
- Poor roads
- Neurosurgical ward , Mulago Hosp admission

- Total=1528
- Head injury= 1077…………………..70.4%
- Tumors = 122…………………………..8%
- Congenital=109………………………7.1%
- Others(stroke, SAH)…………………14.5%
- Boda >> >metallic bars >cars>fall from height
- Risk factor inTBI to PTE
- GCS <10
- Cortical contusion
- Intracranial hemorrhages
- Penetration of the brain
- Seizure with 24hrs after injury
- Classification
- Early < a week
- Late > a week
- Diagnosis
- Thorough History taking
- Neurological exams
- Neuroimaging
- EEG
- Management
- Antiepileptic
- Vagal nerve stimulation
- Surgical resection of epileptogenic lesion
- Life style modification

- Counseling
- Shortcomings during Mx
- Lack os specialists(psychiatric, neoro,etc)
- Lack of equipment
- Expensive antiepileptic Rx
- Conclusion
- Despite several "interventions" used to prevent PTE the only proven intervention to date is to prevent TBI from ocurring !!!!!!!!!
- THEREFORE ALWAYS WHILE YOU ARE ON THE ROAD ASSUME THAT THE REST WILL MAKE A MISTAKE EXCEPT YOU!!!
- *THANK YOU VERY MUCH, WISHING YOU A MERRY X'MAS & HAPPY 2013.*

APPENDIX 3

ATTENDANCE LIST

S/NO	NAMES	SEX	POSITION	MOBILE
1	Odongo Andrew	M	Chairman BOD	0782-498677
2	Kasabiti Mary	F	Gen sec ESAU	0774-703053
3	Atukunda Praise	F	Focal Person	0785-008748
4	Kayigwa Sekasi	M	Sec	0776-951045
5	Namata Lidya	F	Secretary	0787-688373
6	Okello Jacks Jimmy	M	C/person	0782-991669

7	Karode Lazarus	M	C/person	0751-982622
8	Molibira Richard	M	Health Worker FBU	0774-886141
9	Walunguba Thomas	M	PCO	0793-936471
10	Dr Joyce Moriku Kaducu	F	Pediatrician	0772-933707
11	Oketcho Felix	M	Journalist	0752-651749
12	Elias Byaruhanga	M	PPCO	0772-650803
13	Barudawa Fred	M	Camera Man	0751-687533
14	Peder Thorniwe	M	Proj Cord DPOD	0777-789747
15	Among Diana	F	St Philips Gulu	0778-809201
16	Dr Hafsa Lutwaka	M	MOH	0712-445549
17	Museme David	M	Journalist	0712-399836
18	Kiyingi Edward	M	Camera Man	0782-139880
19	Namwanje Saryah R	F	Student	0784-710221
20	Dr Nsada Zachary	M	Lecturer	0772-410773
21	Kojo Daniel	M	N/office	0794-754602
22	Julius Kayira	M	Ex Director	0772-462373
23	Asamo Hellen Grace	F	MP PWDs	0772-475186
24	Okunu Moses	M	Secretary	O773-175091
25	Oluka Francis MundUda	M	Psychatriac Nurse	0777-874002
26	Ikulumet Hellen	F	Treasurer	0754-745505
27	Sr Margret Nangendo	F	In charge	0789-135821
28	Sabiiti Peter	M	BOD Publicity	0774-209426
29	Kabara Francis	M	Chairperson	0783-113252
30	Ttendo Damalie	F	Secretary	0702-825502
31	Edema Joseph	M	Chairperson	0782-928820
32	Balikowa Wilber	M	Treasurer	0752-547878
33	Mugisha Joseph	M	Clinical Officer	0773-266948
34	Tuhumwire Herbert	M	Disability worker	0779-525220
35	Dr Opar Bernard	M	NC-NS	0772-469723
36	Komukyeya Victoria	F	Volunteer USDC	0782-290816
37	Namwanje Hilda	F	Clinical Officer	0779-910840
38	Regina N.M. Kamoga	F	CHAIN	0781-499001
39	Susan Aciro	F	UNAD	0774-700840
40	Kisembo Albert	M	Adminstrator	0782-065385
41	Dailago Annoman	F	CORSU	0752-553750
42	Sr Kahangire Feddy	F	In charge	0782-995854
43	T.P.Otim eseter	M	Chairman	0772-898625
44	Tumusiima Lisa	F	Ass Prog Officer	0779-152199
45	Adiko Yayeri	F	Care taker	0772-587045
46	Khaemba Richard	M	Program Coordinator	0772-322436
47	Atukunda Christine	F	Adminstrator	0782-193475
48	Ocoto William	M	ESAU staff	0702-725632
49	Nakidde Juliet	F	BOD Member ESAU	0785-871866
50	Sebukyu Ahmad	M	C/person	0774-154109
51	Atuhaire Lydia	F	C/person	0782-132953
52	Okidong Richard	M	C/person	0775-552575
53	Esabu Sam	M	Secretary	0759-965757
54	Alaru Muzamil Kuju	M	BOD member	0782-930018
55	Lukanda Jane	F	BOD member	0752-511459

56	Ngobi Alex Pande	M	ACC ED	0712-956901
57	Azza Michael	M	PCO Moyo	0772-337350
58	Kantono Jane	F	EO/SNE-MOES	0774-931825
59	Ssekidde Emanuel	M	Katalemwa Chesire	0701-963945
60	Mugisha Okwera	M	C/Man BYU	0782-941747
61	Okiira G peter	M	P.O Advocacy	0752-774158
62	Inebe Hulda	F	Student	0783-609545
63	Ruth Mukiibi	F	ED SAU	0712-815978
64	Kilama Patrick Sam	M	SC	0772-934471
65	Ekii Patrick	M	PCO	0772-827711
66	Sarah Elirit	F	Sign Language T	0782-658970
67	Amanya John	M	NACARE	0772-998824
68	Dr Matovu Stephen	M	Physician	0772-403134
69	Kenema Jacenta	F	RHU	0781-591716
70	Ssemakula Joseph	M	ED	0753-178349
71	Olanya Dennis Mike	M	SLI	0775-088359
72	Kyarisiima Clare	F	Secretary ESAU	0784-936361
73	Navuga Peace	F	Journalist	0781-491121
74	Nankua Ruth	F	WAAC	
75	Ladia Hanah	F	Participant	0782-198314
76	Kabuye Rashid	M		0701-806686
77	Kirabo Edwin	M		
78	Ndyahika Dickson	M	ESAU Advocacy	0772-327996
79	Sarah Nekesa	F	ESAU Accountant	0777-161687
80	Mugarura Augustine	M	ESAU ND	0774-077589
81	Engole Justine	F	ESAU OD Officer	0702-405386
82	Ocan Paul Oola	M	ESA Logistic Officer	0772-698630