



# EpilepsyAfrica

## News

A newsletter on  
epilepsy affairs in Africa

Issue 1  
January-June 2010

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## Epilepsy in Africa: is there a sustainable way forward?

### Editorial

From Dakar, Lome, Harare, Kampala to Cape-town, ideas have been shared on how to improve epilepsy management in Africa and how to better the quality of life of the more than 6 million people with epilepsy in Africa.

Is it not now the time to concretize ideas? Now is the time to walk the talk, take these ideas with us and better the lives of

people with epilepsy.

After we have started walking, we shall need to keep walking. Keeping walking may seem easy, but shall be very difficult when we get tired or old.

We need to put in place strategies for new players to take from us the button sticks for the race to continue. We need to set guidelines, sustained by a viable coordinating regional committee.

*"I think we need a 3-pronged approach: stronger regional integration propelled by much stronger national associations and deeper networks with our grandest strategic partners, the IBE, ILAE and WHO"*

But the question we all have is what is the most sustainable way forward?

We need to set up permanent structures to complement what the IBE is doing for us. This may include

plans to enhance unified fundraising, awareness, treatment, research, training and advocacy.

Our last option is to keep building the capacity of local associations. But donors now look for regional partners more than they do smaller organisations.

We need to weigh our options, including many others you know of and act for the best and the most sustainable way forward. I think we need a 3-pronged approach: stronger regional integration propelled by much stronger national associations and deeper networks with our grandest strategic partners, the IBE, ILAE and WHO"

J. MUGUMBATE, Harare

## Mr. Zimba visits Zimbabwe during 20th National Epilepsy Awareness

September 21-25 2009 was Zimbabwe's National Epilepsy Awareness Week (NEAW). This was the 20<sup>th</sup> edition of this event, spearheaded by the Epilepsy Support Foundation (ESF), a chapter of the IBE. Mr. Zimba, who is Vice President of IBE (Africa), Chairman Africa Region Executive Committee, Coordinator in the Ministry of Health and Chairman

Epilepsy Association in Zambia was invited. He was in Zimbabwe for the whole week, time he used to meet the Minister of Health, Secretary for Health, Mental Health Coordinator, Health Advisor to President and cabinet and visited hospitals. He had a lecture with about 100 doctors and attended to television and radio programmes. He visited the epilepsy centre and clinic run by the ESF. And was quite embraced by the work being done to uplift the life of PWE from

income generating projects (e.g. the peanut butter project supported by the IBE), youth programmes, women initiatives, computer training and rural projects. and non-government epilepsy programmes.

*Photo: Mr. Kadzviti of ESF and Mr. Zimba upon arrival. Story continued on page 2.*

*Right photos: poverty results in many people not seeking treatment in Africa. Burns and impairments are some of the results. There is need for awareness. Resources for both awareness and treatment are limited. Photos*



## Namibia Celebrates Epilepsy Day

**Harmiena RIPHAGEN** reports

20 June 2009 was the epilepsy day in Namibia. As such, an awareness event was held at Maerua Mall

in Windhoek from 9h00-16h00 in the Mr. Price

promotion area.

We invited people with epilepsy to come to the stand for information, but more important to talk to the public about epilepsy.

We wanted everybody to understand what it is all about to live with epilepsy. Those members with businesses were given an oppor-

tunity to advertise and sell products. The event was quite successful and the association look forward to yet another successful event in the next year.

*Picture: sharing information on epilepsy during the epilepsy week.*

*The writer, passionately known as Miena, is the Coordinator for*



## EPILEPSY KEY FACTS: WHO

- Epilepsy is a chronic neurological disorder that affects people of all ages.
- Around 50 million people worldwide have epilepsy.
- Nearly 90% of the people with epilepsy are found in developing regions.
- Epilepsy responds to treatment about 70% of the time, yet about three fourths of affected people in developing countries do not get the treatment they need.
- People with epilepsy and their families can suffer from stigma and discrimination in many parts of the world.



*Photo: training of health and social service professionals in epilepsy management is needed in Africa but resources limit this noble objective.*

## South Africa's epilepsy week

During the National Epilepsy Week in 2009, Epilepsy South Africa launched a new website. This was necessary to enhance interaction between stakeholders in epilepsy issues. To further enhance this endeavor, an electronic newsletter was launched as well.

The National Office hosted a celebration of partnerships on National Epilepsy Day in the form of a Candle Lighting Ceremony. This was beefed up

with National Radio interviews and exposure in national newspaper publications.

### [Comment on epilepsy weeks and days in Africa](#)

The celebration of these events is limited in scope due to a general lack of resources. Unifying these events across Africa has been on the agenda for many years but with no tangible progress. The African

declaration (Dakar, Senegal, 2000) calls for Africa to declare an Epilepsy Day . It may be very difficult for nations to agree on a day or week because of their current events. But it is practically possible to adopt one day for the region while maintaining traditional ones. This increases the voice and multiplies recognition of the fight against epilepsy.

**If you have any ideas on how to improve such events do not hesitate to inform us.**

The IBE Vice President for Africa and Chairperson IBE Africa Executive Committee graced Zimbabwe's 20th edition of the National Epilepsy Awareness Week from 21-25 September

*Continued from page 1*

He lamented the lack of resources to develop the epilepsy centre, particularly shortage of staff and medication.

Mr. Zimba emphasized the separation of neurological conditions from mental health conditions in terms of programming and management. There is need for a focal person for epilepsy, a budget and activities for epilepsy. Need for government and non-government support to government.

## Putting up a case for an ILAE commission in Africa

Last year, Paul G. Kioy drafted a document to put up a case for an ILAE commission for Africa. This follows deliberations at the congress where the ILAE tasked members from Africa who were present to engage other chapters of the ILAE in the region to see if the ILAE should

put up a commission for Africa.

It is the region's considered opinion that such a move is long over due and people in Africa are ready to play a major role in this regard.

Early this year, ILAE President Dr. Moshé wrote to African Leagues "...the Executive Committee of the



ILAE has asked Dr Lionel Carmant, past President of the Canadian League Against Epilepsy, to represent the League in working with the African ILAE chapters to help as needed, in creating the African Commission." This confirms the keen interest ILAE has in Africa and we are all ready to see this goal being achieved.

## Epilepsy Clinics in Africa: the case of Kenya, Zambia and Zimbabwe

**Kenya, Zambia and Zimbabwe all run Epilepsy Clinics. These clinics are models for epilepsy management in their countries and in Africa. However, they face serious challenges.**

### Challenges facing epilepsy clinics

- Unavailability of adequate medication.
- Inadequate personnel
- High default rate among patients due to poverty as many often cannot afford the cost

of drugs and transport for frequent clinic visits.

- Lack of sufficient funds to purchase drugs by the patients.
- High level of ignorance among the patients due to lack of knowledge on epilepsy.
- Poor drug compliance of patients due to strong cultural beliefs on traditional medicine. In addition high patient expectations for immediate cure has forced many to move from one doctor to another thus affecting their treatment compliance considerably.
- High turn-out of patients in KAWE op-

erated clinics results in congestion within the city council facilities.

### Appealing for support

We appeal for support from the world in order to rescue these and many other such initiatives in Africa.



*The Nicholas George Epilepsy Rehabilitation Centre with a Clinic in Harare Zimbabwe run by the Epilepsy Support Foundation.*



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This newsletter is published 2 times a year in January and July and distributed by email to subscribers as well as on the IBE website. Contact the Editor so that you can receive a copy by email or to alter your mailing details.

Articles are welcome.

## Zimbabweans appreciate the IBE

At the Annual General Meeting of members of the Foundation held on 3 September 2009, the IBE was awarded the annual appreciation award for support in 2008 with funds that ran the Promising Strategy Programme in Buhera District. This resulted in the formation of the Buhera branch after more people with epilepsy turned up for treatment.

## Testimony: overcoming epilepsy in Uganda

### TURNING CHALLENGES INTO OPPORTUNITIES WITH EPILEPSY

In 1983, I fell sick, 3 days after I had completed my PLE examinations. This was a very a strange illness to the family and I was bedridden for two months, and later recovered without medical treatment, except on traditional medicine.

Three years later, I started experiencing sight Problems with pain in my eyes and could not read well. I was taken to the hospital for medical checkup and they found no problem with my eyes and this continued for a long time

My first attack happened at school in senior 5, I became unconscious for some time, I later recovered but with bruises. Students were looking at me with shock, this became a common phenomenon.

#### Personal Challenges

- Constant pain
- Restriction in movement

- for fear of getting fits
- Feeling of committing suicide
- Lack of friends
- Personal adjustment to new changes
- Discrimination in employment
- Verbal abuse
- Stigma and prejudice from the community

#### Becoming ESAU Member

I joined to become a member of ESAU in 2002 with Apac Town Council Epilepsy Support Association Branch where I received counseling, shared experiences and support on how to manage epilepsy and acquire treatment

#### Benefits of being ESAU member

- a) Personal management of epilepsy
- b) Training in leadership skills
- c) Training in financial management

- d) Gained confidence
- e) Attended a Course in Denmark through ESAU
- f) Elected General Secretary ESAU BOD



*Photo: Awareness methods like these have eased the burden of people with epilepsy in Africa but more needs to be done.*

#### Conclusion

For 3 years now I have not had Fits but experience some mild sign. I am now living a decent and responsible life. Thank you to ESAU and the Psychiatric Clinical Officers Apac Hospital who are helping People with Epilepsy Together we can help to bring epilepsy in Uganda out of the shadows.

#### Dan, ESAU Member

#### In the Next issue



⇒ Peanut Butter and Gardening projects in Zimbabwe and Zambia and many lessons from other Promising Strategies



⇒ Drug Bank in Uganda and other countries

⇒ Youth with epilepsy (ywe) initiatives

⇒ Activities for 2010



**Call for reports/articles:** if you have a report to do with epilepsy in the Africa region, please do not hesitate to submit it for inclusion in next issues of the newsletter. African chapters are particularly asked to use this newsletter opportunity to inform the world about the important work they are undertaking under severe resource constraints. We look forward to have your report in the next issue.



# 2010: EPILEPSY IN AFRICA

The Executive Committee pictured below met from 12-16 January 2010 in Capetown South Africa and this was their first meeting. The meeting came up with a strategic plan that shall be communi-

### In brief

**Reports and articles:** The Committee resolved that all associations in the region should send regular reports. Communication shall be done on the procedure. The committee recommends all associations to submit articles for the newsletter that shall be published in January and July each year.

### Mind your language

Lets use 'people with epilepsy, person with epilepsy' as opposed to epileptic. Lets use condition as opposed to disease when referring to epilepsy.



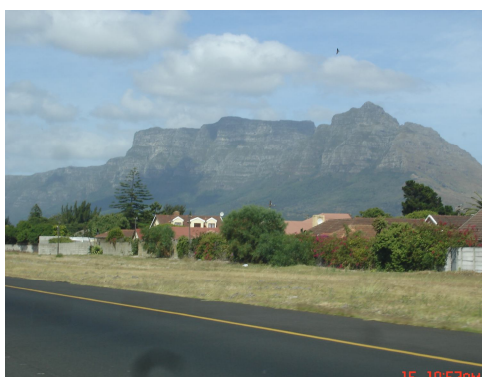
cated. The meeting was attended by Mr. Zimba, Mr. Mugumbate, Mrs. de Goede.

Photo from left: Anthony, Jacob, Augustine & Noeline.

The Executive Committee took time to visit various epilepsy initiatives run by Epilepsy South Africa. What we saw can only be described as



'amazing'. We all commended ESA for the massive work they are doing to uplift the life of people with epilepsy. Check these pictures. The Zulu chair made by Zulu. Mamas, a mate, seat covers all made by men and women with epilepsy. A Director at one of the Centres together with 3 women making mates pose for a photo with members of the executive committee. Below: Table Mountain is Capetown's major landmark.



## What are you doing in 2010? Share with us for publication in the next issue of the newsletter.

Have you sent your 2009 report? If not yet please email it to the Secretary as soon as possible.

If there are people with epilepsy who have excelled in your own association or country in general, please tell us about them so that we share their experiences. The Executive Committee encourages associations to promote the participation of people with epilepsy in their activities. See you in the next issue.





# FOCUS ON ZAMBIA

In each issue of the newsletter, a section shall be devoted to the work of a single association in Africa.

In this first issue we are dwelling on Zambia, which was chosen because of the number of articles it submitted for the newsletter. *Left: Logo Zambia Epilepsy Association (ZEA).*



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The Epilepsy Association of Zambia founded in 2001 and its main objective is to address the needs of people with epilepsy. The Association in collaboration with the Ministry of Health and WHO launched Epilepsy Campaign Zambia Program whose theme is '**Epilepsy Out of Shadows**' in 2003. Since the launch of this program, many sensitization activities have been carried out and as a result a lot of people with this condition have come out to access medication and many have become seizure free.

**Treatment:** In Africa, if communities are made aware that epilepsy is treatable, they turn out for treatment in numbers. Unfortunately, resources for awareness are limited and when they turn out for treatment, they find understaffed clinics with no anti-epilepsy drugs. This photo shows an Epilepsy Clinic in Zambia at St. Patricks in Chipata Compound, Lusaka held in collaboration with Cheshire Home CBR Mandevu.



**What have you done in the first half of 2010? Share with us for publication in the next July to December issue of the EpilepsyAfricaNewsletter.**