



INTERNATIONAL BUREAU OF EPILEPSY CONGRESS REPORT

28th August- 2nd September 2011

In this report the author a beneficiary of the Finland government through the support of Finland Epilepsy Association attended a six day congress in Rome, Italy. There is no way actions or words that would suffice the satisfaction of a person with epilepsy (the author) to benefit from such a partnership that stands to help all Malawians living with epilepsy. Never would a you imagine a marginalized group in their own country struggling to voice their concerns to be among doctors, researchers and advocates form all over the world under one roof and speaking the same language – epilepsy. Not all could be written and this is a summary of main benefiting points for Malawi

Day 1 – International Bureau of Epilepsy Workshop had three major highlights;

- i) Strategies on working with policy makers
- ii) Advocating from inside by a Member of Parliament
- iii) Funding crisis in epilepsy work

These points highlighted that it is only here in developing countries were working strategies have to be devised. The examples given highlighted that with enough support the work can be light and easily achieved. The lesson learnt being that in Malawi we need to work eith policy makers to advance our goals if we to succeed.

The opening ceremony highlighted how social epilepsy work started 50 years ago and how fitting it was to celebrate it in town it was founded.

The awards ceremony was also a learning experience with one Social Accomplishment Award winner Pravina Shah who proved that by limited resources and good selection of the target group epilepsy barriers can be overcome. Malawi being one of the poorest in the world has a leaf to copy from India on how they have mobilized school children to be agents of change.

Day 2 – The main highlight of the day considering the work in Malawi was a presentation by Esper Cavalheiro from Brazil entitled “Enlisting the governments in the war against epilepsy”. It was highlighted that it is not the wealth of a nation that makes its people health. Poor nations like Malawi can also have healthier citizens using limited resource as long as priorities are considered wisely. In developed countries healthcare is just but a label with the majority of people suffering or not knowing its benefits. United States was sited as one such example. Therefore this highlights the need to have good systems of management especially were resources are limited.

Lastly on the day I had a meeting with the Danish Association and highlighted to them the issue concerning epilepsy drug shortage in Malawi.

Day 3 - An International Bureau of Epilepsy Africa Workshop was held in the good part of the morning. The main issue discussed was the first African Epilepsy Congress to be held in Kenya in June 2012. It was motivating to meet other epilepsy advocates, researchers, doctors and other well wishers as we shared experiences and challenges of epilepsy work.

In the late morning a parallel session looking into epilepsy investment looked unto efforts done in Zambia, Chile and China. During this session I had a brief contact with Mike Glynn who promised to support the efforts once registered as a member association.

During lunch we had a brief meeting with the Finland Epilepsy Association team. It was encouraging to meet after years of correspondence by mail. Not detailed information of the work in both countries was discussed. A detailed meeting was planned for Thursday evening together with Denmark Epilepsy Association and Uganda Epilepsy Association.

An abstract by this author had been accepted by the congress and I presented the study I carried entitled “**Prevalence, treatment gap and education level of PWE in Malawi**”. It was

interesting to having questions on the work done in Malawi, Congress delegates from Madagascar, Italy, India, England and Democratic Republic of Congo showed interest in the presented asked for notes on the presentation. The Finnish team also was in the audience ton listen to the presentation.

Day 4 – I had an opportunity to attend a morning teaching session which looked at synergizing and advocacy looking at working together between the professional and social bodies of epilepsy. Malawi as a nation with only a social association learnt that teamwork with any other emerging group is essential if success is to be fully achieved in this work. A presentation by Vinod Saxena highlighted sighted how difficult the bridging was difficult..

The whole afternoon was devoted to the International Bureau of Epilepsy General Assembly. Efoorts done during the past two years including new members joining was discussed. Additionally business matters of the Bureau were also discussed. A project called Hand over Hand was introduced which aims at having photos of youths with epilepsy taken together with countries sports person who are achievers. At the end it was the International Bureau of Epilepsy Jubilee celebration commemorating the achievements of 50 years ago.

An evening meeting took place together with Denmark Epilepsy Association and Uganda Epilepsy Association. The reason for involving the two ,mentioned associations was to learn how they have collaborated for years in the epilepsy work and learn from the challenges they faced. This would in future help Finland Epilepsy and Malawi Epilepsy Association for future work. The meeting gave Malawi all the courage, strength and hope that the fight against marginalization can be won. “There is a lot of hard work that is needed and you have already started that work.....” said Sari Tervonen the Executive Director of Finland Epilepsy Association.

The partnership between Denmark and Uganda also brought lessons on what barriers are usually faced by partnerships between developed countries and their African counterparts:

- 1) Language
- 2) Culture
- 3) Environments
- 4) Expectations

It was interesting to hear experiences of how people with epilepsy are regarded in Finland. Of interest also was to know how the system is so different to our setting in Malawi and see many people with epilepsy involved in the uplifting of their lives through the association,

Additional benefits of the congress

Networking

I was able to meet representatives of Denmark and Norway epilepsy associations who wished us well in our endeavors of seeking support and pledged that they would see if they would help us here in Malawi.

I was also in contact with both the President of International Bureau Epilepsy and he personally encouraged us to come on board with the experience gained in Malawi. He pledged his full support once a full member.

One-on-one discussion

I had benefits of learning from Kenya the Kilifi area where Dr Charles Newton set up a model epilepsy clinic. The centre has facilitated many researches on epilepsy and I learnt a lot from Carol Mbuba who works for this Welcome Trust in Kilifi.

Democratic Republic of Congo, the only country in the great lakes region represented at this congress has a model program on awareness of setting up a radio station to educate people about epilepsy and main other health conditions. This radio station has proved to be a cash cow for the epilepsy project which proved to me that sustainability can be achieved as long as innovative ideas are put into action.

The platform presentations were so up to date and relevant to modern day epilepsy and enlightened us the need to have more research and training in trying to improve the lives of people with epilepsy.

New therapies that have been recently found were presented in symposium form or posters and all this proved that Malawi is far away from coming out of the shadows of epilepsy unless a helping hand is found. Malawi still relies on old drugs which are however effective in reducing seizures in our context of want.

Modern testing equipment such as MRI and EEG machines were on display and Malawi needs to waken up to catch up with this modern technology though it is accepted that "Rome was not built in a day".

This is just about all that the congress benefit Malawi and dissemination of lesson learnt have already been presented to some stakeholders i.e two radio stations, and to our newly elected executive committee which I am now the President and this happened on the 17th of September, 2011. Additional programmes shall highlight the assistance Finland rendered to Malawi during this congress during our Epilepsy Day on the 29th of October, 2011. The Epilepsy week which kicks off with a press briefing will also help to highlight the lessons learnt at the congress and show how many people through national, regional and international efforts can benefit team efforts.

Plan of dissemination

MIJ Radio – two programs (one featured already)

Capital Radio – one program

Joy Radio – one program

Zodiak Broadcasting – two program(one featured)

Daily Times (Feature Story)

Nation Daily(News Item)

In conclusion it is Malawi's' wish to work with the Finland Epilepsy Association (FEA) on a long term basis and learn more from the experience of FEA. On behalf of our association we would like to thank FEA for the support rendered before and after the congress. Additionally, I would like to thank the Finland government for the support rendered through FEA. It is our hope that the FEA will continue to support the epilepsy efforts here in Malawi through all means possible.

Unfortunately one of the expected participants Chimwemwe Pindani Tembo failed to attend the function because of late congress registration and was not able to fulfill all the visa requirements on time.

Action Amos

