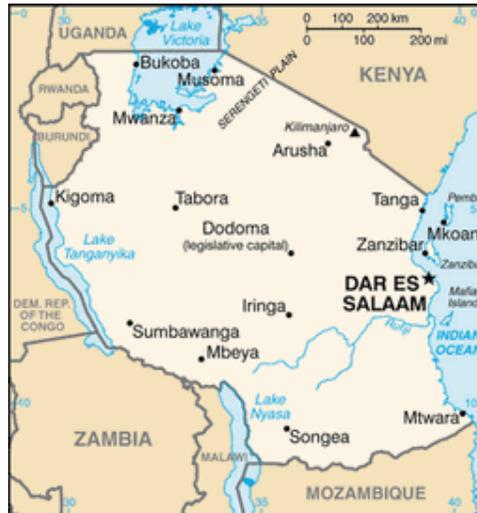


Republic of Tanzania Map



REPORT ON THE VISIT TO PARENTS OF CHILDREN WITH EPILEPSY- TANZANIA

BY ANTHONY M. ZIMBA CHAIR /VICE PRESIDENT IBE AFRICA REGION

12-15th January 2011

Introduction

The visit to Parents of children with epilepsy in Tanzania (POCET) was under taken from 12 - 15th January 2011. The purpose of the visit was to learn the difficulties the organization was facing as they had not been communicating both to the international Bureau for Epilepsy headquarters and Africa Regional Committee.

POCET'S BACK GROUND

The parent's organization of children with epilepsy – Tanzania (POCET), was formed on 12th June 1992. It is a registered as a non governmental organization with Tanzanian government registrar of societies and given registration no. SO.7674. It has a membership of 900 on record and only 50 of these are paid up members.

The formation of the organization was initiated by Dr. Martha Collins, while Professor Meinardi a support member from Netherlands helped the organization to be affiliated to the International Bureau for Epilepsy (IBE).

The aims and objectives of the organization are:

1. To work together using the resources of parents, guardians' caretakers and other interested persons in order to obtain the best possible care for children with epilepsy.
2. To help solve problems concerning the acquisition and/or procurement of anti-epileptic medicines.
3. To attempt to follow-up all feasible ways to purchase medicines at the best possible prices.
4. To cooperate with other Organizations which are engaged in the education of the public concerning epilepsy.
5. To work together in understanding childhood epilepsy by doing research.

The organization was formed at the time the epilepsy patients and carers were having problems in securing anti-epileptic drugs from government health institutions. The organization after its formation managed to raise funds to set up a drug bank for anti-epileptics drugs which were sold at a low cost to the patient's parents and carer's. Those who could not afford to buy were given free. The proceeds from the sell of drugs were used for running POCET office and purchase of a 54 acre piece of land which is used for farming activities.

The farming activities have now slowed down because the government since 2005 has been providing free anti-epileptic drugs to all its health facilities. The patients no longer buy medication from the Association which has put the Association out of some income to run the organization activities including the farm. Though this has put the organization out of income generation, It is to the advantage of patients and the carers, who no longer pay for medication.

Association Structure

- | | |
|------------------------|-----------------------------------|
| 1. Chairman | Dr. Richard Sillo (Vet Dr) |
| 2. Vice Chairman | Dr. Makene (Medical Dr) |
| 3. Secretary General | Mrs. Matowo (Nurse/Social worker) |
| 4. Vice Secretary | Ms. Jane Mwenda(Nurse Therapist) |
| 5. Treasurer | Mr. Kaijage (Accountant) |
| 6. Assistant Treasurer | Ms. Beatrice Nsimba (CPN) |

MEETING



The first day of my visit I held a meeting with three POCET members in the Psychiatric department boardroom.

Mrs Matowo, Mr. Kaijage and myself at the Hotel

After the meeting I was taken round the hospital and visited Social work department, Outpatient and EEG department. I had also opportunity to talk to the fifth year finalist

Medical students and encouraged them to take interest in neurological studies. The students were very happy and requested for more information and the possibility of them attending international epilepsy forum meetings.



Meeting Fifth Year Medical students at Muhimbili University students Epilepsy Clinic at Muhimbili University Teaching Hospital

Visit to Ministry of Health Headquarters

The meeting was held with Dr. Joseph Mbatia Mental health Director at the Ministry of Health Headquarters. He highlighted the efforts the government was making in addressing epilepsy issues in Tanzania especially in the provision of Antiepileptic drugs through out the country. The Director was briefed about work of the International Bureau for epilepsy in the Africa region. The Director was requested to request the Ministry of Health to assist members of POCET to be attending International Epilepsy meetings, launch Global Campaign against Epilepsy Program (GCAE) and establish National Epilepsy Day in Tanzania.

Guidelines on the GCAE program will be sent the Ministry of Health and POCET Secretariat in due course.

A suggestion was made to the Director to consider delinking epilepsy management from mental health as this practise which is very common in many African countries usually promotes stigma and mismanagement of epilepsy patients.



Visit to MOH offices (Dr Mbatia)



EEG Department

Promising Strategy Project

In 2007 the organization applied and was granted \$5000 from IBE under promising strategy project to embark on Cashew nuts and vegetable growing project. The first instalment of \$3750 was received on 14th March 2008. From the funds received, 15 acres of land was used to plant 500 Cashew nuts trees and 4 acres was used to plant a variety of vegetables.



Secretary General Holding small cashew nut tree



POCET Volunteers and Members at the farm

For few years the farming activities did very well but later faced a problem of animals attacking crops as the organisation could not afford to build a structure and employ some one to take care of the place. Currently the farm is being looked after by three village volunteers who live in the near by village. As a way to encourage these volunteers, they have been allowed to harvest Cashew nuts whenever they are in season. This arrangement of barter trade though it cannot be avoided, has left the organization without any income.



Volunteers pruning Cashew nut trees at PO CET farm



Pineapple grown at PO CET'S farm

Other Activities

The past few years the Association held the following activities:

1. In 2003 the WHO donated \$1000 which was used to print brochures, T. Shirts, paying the drama group, school competition , Radio and TV epilepsy program and held epilepsy workshop for health workers and primary school children.
2. Distributed a questioner in schools and among health workers on the knowledge, attitude and practice.
3. The organization in collaboration with Tanzania Epilepsy Association conducted a knowledge and attitude (KAP) survey in Schools, Health centres and Traditional Healers with the support of \$2000 from Novartis.
4. A joint one day symposium was held for health workers on the care of people with epilepsy Dr Joseph Mbatia from the Ministry of Health was the guest of honour.

Constraints

1. Lack of funds to run the organization activities
2. The organization does not have an office
3. Lack of support from the Donors and the community in spite the fact that the organization has sent out many proposals to the Donor Community and Local Companies
4. Lack of funds to develop the organization farm

Recommendations:

1. The government through Ministry of Health and in consultation with WHO Country Office, Tanzania Epilepsy Association and PO CET, should consider launching Global Campaign against epilepsy Tanzanian Program. The day the GCAE will be launched could be considered as Tanzanian National Epilepsy Day.

2. Since POCET is the only social aspect organization affiliated to IBE in the country, constitution amendment should be considered to accommodate other people with epilepsy, instead of the current scenario where the organization is specifically for the parents with children living with epilepsy.
3. POCET should be supported by the relevant ministries, NGOs and the Donor community to acquire a title deed for the beautiful 54 acre farm land they have and also help to develop it into a viable project for the benefit of the people living with epilepsy and those others with special needs.
4. POCET members should be supported to attend international Epilepsy meetings.
5. POCET should be helped to secure an office for its operations
6. POCET members should be regular and prompt in communication with IBE office in Dublin and Africa region Secretariat.
7. POCET should intensify local fundraising activities i.e. Fundraising walks, tea parties, car wash, Golf tournaments, casual day etc instead of depending only on soliciting donations from, government and the donor community.
8. POCET should collaborate with other local and International NGOS with interest in the care of people with epilepsy (see www.ibe-epilepsy.org).
9. POCET in collaboration with Tanzania Epilepsy Association should work towards expanding epilepsy activities to all Tanzanian regions and districts, instead of concentrating only in the capital city.
10. POCET should consider to elect some members living with epilepsy to sit on the executive committee (currently there is none).
11. Since POCET is a social aspect organization some Key positions such as Chairman, vice, Secretary General Etc should not **necessarily be held by Senior Medical Officers**, as their positions are too demanding to address patient's social issues.

Conclusion

My visit to POCET was very fruitful and gave me an opportunity to see for myself how the organization is struggling to survive. The organization leadership is very dedicated but they need support as mentioned above.

This report is based on my observation and what I feel would be of help if adopted in line with the local government policies, but not as a directive to the organization and its co-operating partners.

I would like to thank Air Masters my organization (Epilepsy Association of Zambia) Travel Agency who donated return Air ticket to enable me under take this important trip. Part of the trip was self sponsored.

I would not like to forget Prof Paul Kioy of Kenya Epilepsy Association whom I met for the second time during the ILAE meeting last December in Dakar, Senegal for having connected me through email me to Prof William Matuja Lecturer of MUHAS and member of Tanzania

Epilepsy Association, whom I should salute for having helped me to locate and communicate to POCET executive members before I travelled.

Special thanks should go to the Tanzanian Ministry of Health Mental Health Director Dr. Joseph Mbatia for rescheduling his precious work to have a meeting with me and the POCET team.

Many thanks also should go to the three POCET executive members; Aisia Matowo Mrema Secretary General, Edward Kaijage Treasurer and John Chiwata POCET Member who at the same time is Tanzania Epilepsy Association Secretary. I would like to sincerely thank them all for having sacrificed their precious time and transport to have meetings with me and taken round to visit places and the farm.

Last but not certainly the least I would like to thank my Ministry of Health through Chainama Hills College Hospital my work place for grating me leave which enabled me to undertake the trip.

I would have loved to meet all POCET members and other stakeholders but due to limited time and resources it was not possible. I hope and trust that the good Lord will afford me another opportunity in the nearest future to visit and follow up the re commendations I have made in this report.

God bless you all as we struggle to bring Epilepsy '**Out of the Shadows in Africa**'

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Tanzanian Flag



IBE Logo



Zambian Flag