

# EPILEPSY SUPPORT ASSOCIATION UGANDA (ESAU)



## 2012 ANNUAL REPORT



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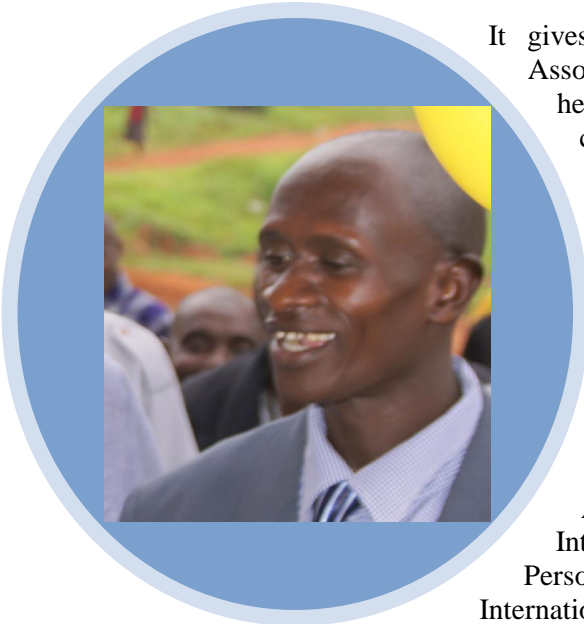
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## FROM THE CHAIRMAN ESAU BOARD OF DIRECTORS



It gives me great pleasure to write about the Epilepsy Support Association Uganda (ESAU) which i have been associated with since her inception. It is gratifying to note that in 2012, ESAU has continued to attract persons with Epilepsy, guardians and other well wishers.

I am grateful to all the members, staff, board and all our partners whose efforts and good will has kept the candle burning in ESAU. In this 2012 Annual Report, i wish to draw the attention of the Government of Uganda, policy makers, Professionals and the general public to the plight of People with Epilepsy.

ESAU would like to thank her donors, the Danish Epilepsy Association (DANIDA), the Swedish Development Agency, and International Bureau for Epilepsy, National Union of Disabled Persons, and National Union of Women with Disabilities in Uganda, International Alliance of Patients Organisation, and Voices of Health

Rights for the financial support they have provided and enabled programmes of the Association to smoothly operate. We hope this spirit of networking and cooperation will continue in the coming years.

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 all health centres through National Medical Stores. We hope this process will continue and that more health centres will get more of these Anti Epileptic medications timely in the forth coming years.

In the year 2012, Medical Practitioners have written that Nodding syndrome is a type of Epilepsy. I would like to encourage the Government of Uganda through Ministry of Health to come out clearly and declare themselves on the same, so we are able to mobilise our members according to the Government declaration.

I want to appreciate the environment created by the support of District Local Governments for People with Epilepsy in the year 2012. 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. We pray this cooperation continues for the benefit of persons living with epilepsy indefinitely.

In the years to come, ESAU hope to continue with her work of Awareness raising on Epilepsy, Advocacy, Counselling and referral of people with epilepsy. In the next two years, we 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 appeal to all members to embrace ESAU's development plans in the coming years and make ESAU more sustainable. I also request our development partners to continue their support so that together we can be able to reach those whom we have not yet reached and be able to bring epilepsy in Uganda out of the shadows and serve PWE better.

**Odongo Andrew-ESAU BOD Chairman**

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## FORWARD FROM ESAU NATIONAL DIRECTOR



I have the greatest pleasure to present the 2012 Annual report to the board and all our partners. ESAU

Continued to grow its membership and make significant Achievements in the past year due to the continued support from its membership the board and our development partners. The most notable achievement was the fact that ESAU was able to complete and occupy its own office building in Wakiso Town Council. Construction of this building had been started in in Jan 2011. It is gratifying therefore that ESAU using its own internally generate funds was able to complete this building in only 18 months. For this feat am eternally grateful to the membership and the board

Am greatly indebted to our development partners who through the last year continued to provide the resources that enabled us to reach more people with epilepsy in the 36 districts where we operate. The Danish Epilepsy Association, Disabled Peoples' organization Denmark (DPOD) and the Swedish Embassy provided the biggest amount of money that we used. Our other partners included NUDIPU, the International Association of Patient Organisation and the International Bureau for Epilepsy (IBE).

For the first time in our history, ESAU ventured into northern Uganda and opened activities in Gulu District. Despite all the prejudices we had been scared of we are happy to note that in one year, we were able to mobilize more than 300 members at both St. Mauritz health centre in Laroo Division and St. Phillips Health centre in Layibi Division. We have been encouraged by the fact that all these members have understood the need to stay on regular medication and are contributing to their medication at these units. EAU is indeed grateful for the support and partnership of the two church not for profit health units in Gulu. These add up to the other 56 not for profit health units spread throughout the country that ESAU continued to work with to provide regular and affordable epilepsy medications to persons with epilepsy.

The onset of the nodding syndrome in parts of Acholi was a low point in the year. We are grateful to the government and other development partners for their quick reaction to this crisis. We are specifically happy that for the first time in Uganda government agreed to introduce sodium valproate in the public health system. This is so far the most efficient treatment for epilepsy available in the country. In addition to this we are grateful to the Ministry of Health and the National Medical Stores for improving the supply of medicines in the country which has resulted in better availability of anti convulsants at health centres in the country

In the coming year, we will continue to strengthen the networks that we have built in the past and it s our commitment to create a better understanding of epilepsy in Uganda.

**Augustine Mugarura-ESAU National Director**

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## 1.0 INTRODUCTION

Epilepsy Support Association Uganda (ESAU) 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 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. The association mobilizes people with epilepsy to form support groups through which they can meet to share experiences, offer each other mutual support and lobby for better services.

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.

## 1.1 ESAU VISION, MISSION, VALUES AND PRINCIPLES

### VISION

A Ugandan society in which epilepsy is understood and People with Epilepsy (PWE) are treated with dignity so that they can exercise their full potential and participate in all development processes.






### MISSION STATEMENT

To become the leading Organisation that empowers people with epilepsy to participate in development processes through advocacy, networking, research and documentation.

### OBJECTIVES:

- a) To build an association in which PWE, their relatives and guardians are empowered and participate in advocacy and lobbying for their rights in achieving dignity and equal opportunities
- b) To empower ESAU structures engage decision makers at the district and sub-county levels for effective service delivery
- c) To create awareness among PWE, their relatives, health workers, opinion leaders and the community so that they can understand epilepsy and are able to support PWE.
- d) To build networks and alliances through which ESAU can advocate for the rights of PWE's.

### ESAU PRINCIPLES

-  Participation
-  Empowerment
-  Networking
-  Non-discrimination
-  Gender equity

### ESAU CORE VALUES

-  Self help
-  Empathy

- ✚ Positive living for PWE
- ✚ Equity
- ✚ Honesty
- ✚ Human dignity
- ✚ Transparency and accountability
- ✚ Love for humanity
- ✚ Service above self

## **1.2. BACKGROUND TO THE ANNUAL REPORT**

2012 saw ESAU ran a number of projects that were funded by different donors. These funders included Danish Epilepsy Association (DEA) through DANIDA, Swedish International Development Cooperation (SIDA) and International Bureau of Epilepsy (IBE).

The main themes addressed under these included; Awareness Raising, Advocacy, Organizational Development, Monitoring, Networking, and Fundraising & Resource Mobilisation. All the projects funded were in line with the Association's mission, vision, objectives and strategic plan.

## **2.0 ESAU ACTIVITIES CARRIED OUT IN 2012**

ESAU activities were carried out under the following themes of;

- 2.1 Awareness Raising**
- 2.2 Advocacy and lobbying**
- 2.3 Organisational Development**
- 2.4 Monitoring and support Supervision**
- 2.5 Networking**
- 2.6 Fundraising and Resource mobilisation**

### **2.1 AWARENESS RAISING**

#### **2.1.1 Demystifying epilepsy through forum theatre.**

ESAU in partnership with Creative Options Uganda Limited (COUL) under the mini project funded by DEA through an application to DANIDA concluded a project whose major aim was raising epilepsy awareness in order to create a better understanding of epilepsy through use of Forum Theatre.

ESAU and DEA had identified Forum Theatre as a tool of providing accurate information on epilepsy. In the year 2012, the mini project that targeted sensitizing young professionals on epilepsy in order to enhance a better understanding was concluded in June 2012.

The forum theatre play highlighted the challenges of PWE and what citizens need to do to help them. The play encouraged young professionals, health workers, parents of PWE and PWE themselves to have a friendly dialogue and understand epilepsy better; epilepsy medication, causes, First aid, types of epilepsy and general management were clearly articulated and emphasized.

**Objectives of the Project.**

1. To create awareness about epilepsy among selected communities by 2012, through Forum Theatre.
2. To reach professionals (teachers, nurses, police) with accurate information on epilepsy so as to influence their attitudes positively towards persons with epilepsy.



The two year project managed to reach a total number of 20,739 people. From this total 10,273 were males while 10,466 were females. In all the institutions visited, more than 80% of the participants had limited information about epilepsy and some totally knew nothing. However, efforts were made by COUL to make them understand the condition better by involving every participant while ESAU staff /Representatives would provide literature after the presentation and make a brief summary speech and answer some questions and refer interested people on where to access medication.

*Table showing summary attendances of the Mini project for the Project period 2010-2012*

Years	ATTENDACNE		TOTAL
	MALES	FEMALES	
Year One	4,128	3,356	7,484
Year Two	6,145	7,110	13,255
Total	<b>10,273</b>	<b>10,466</b>	<b>20,739</b>

**Observation and lessons learnt**

- ✚ It was realized that most people have a lot of misconceptions and lack facts about epilepsy in our society the audience’s opinions would seem to show that epilepsy is some kind of a curse or traditional illness

- ✚ In some of the institutions visited, most students wanted tips on first aid, medication, and where to refer PWE. A number of participants were interested in knowing where PWE could be referred for treatment and whether epilepsy was a treatable condition
- ✚ Most communities and institutions visited, community drama groups and students respectively showed interest to be given an opportunity to act the play themselves and continue raising epilepsy awareness in their respective communities.
- ✚ Participants agreed to support PWE and send them to the nearest health units for treatment and other related support.
- ✚ Participants were grateful for the initiative as it was the first of its kind in the area of raising epilepsy awareness. Most people requested and hoped that more performances could be staged in their respective Districts.

## 2.1.2 IBE School Epilepsy Project

### Introduction.

With support from International Bureau for Epilepsy, ESAU is partnering with Secondary schools to facilitate the implementation of different activities that are aimed at increasing awareness about epilepsy, provide accurate information on the same condition, build the self esteem of school going children, give facts to school administrators and teachers so that epilepsy is brought out of the shadows in Uganda. The project aims at forming epilepsy clubs in 15 secondary schools in Kampala schools to make epilepsy information flow more efficient and accessible.

### Why epilepsy clubs?

Students living with epilepsy in Uganda are faced with a lot of stigma at school which forces them to keep silent about their condition. Worst still, the teachers are not aware of the many ways to positively handle epilepsy cases in their schools and so the students ill equipped to provide even basic first aid to their peers at school. This has put students with epilepsy in risky positions and many have dropped out of school, this provides a challenge of increased number of persons living with epilepsy with inadequate skills to favorably compete in development work, thus increasing the dependency burden.

### Strategy

In the year 2012, ESAU is partnered with Secondary schools to facilitate the implementation of different activities that are aimed at bringing epilepsy out of the shadows and building self esteem among school going children, give facts to school administrators and teachers. These activities included Sensitization meeting with teachers at ESAU offices in Wakiso and sensitization meetings in schools.

### Expected outcomes

This project, which shall still go on in the year 2013 intendeds to create a platform for free and open discussions about epilepsy care and management in schools, increase openness of students with epilepsy and reduce stigmatization drop out cases as a result of epilepsy.

The project anticipates to foster the skills of persons with epilepsy to be able to favorably compete with their counterparts in their respective schools and communities, thus reducing the dependence burden to government and the environments they live in.



**ESAU Staff sensitizing students and teachers of Kitante High School as a way of raising epilepsy awareness and providing accurate information in Kampala.**

In 2012, the project has been aiming at equipping school administrators, teachers and other related staff with epilepsy facts especially on the causes, first aid and where to refer persons with epilepsy and in the year 2013, ESAU anticipates to continue with the same strategy to achieve the expected outcome in the years to come.

### **2.1.3 Tailor-made and Customized Brochures produced**

In a bid to create awareness and reach to different communities and persons with epilepsy, the association printed brochures leaflets twice in the project period. This information and education materials have helped in creating awareness to scores of community members. This has helped in the realization of supportive communities towards persons with epilepsy. ESAU pledges to continuously sensitize communities on the plights and needs of PWE's

### **2.1.4 Production of the epilepsy Torch**

Media is one of the most important means of information dissemination and awareness raising and is seen to play a pivotal role in the fight to bring epilepsy out of the shadows in Uganda. This year, ESAU produced an epilepsy torch and was put in Monitor News paper as an insertion. This helped ESAU to reach different people with epilepsy information, spearheaded debates and discussions on epilepsy among citizens.



## 2.2 ADVOCACY AND LOBBYING

### 2.2.1. National Epilepsy Advocacy Conference

As a way of advocating for people with epilepsy, Epilepsy Support Association Uganda organized a one day Epilepsy National Advocacy conference on the 7<sup>th</sup>/Dec/2012 at Grand Imperial Hotel Kampala.

#### 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

#### Topics Addressed

For better advocacy purposes and proper understanding of epilepsy, ESAU invited several speakers who gave key address notes during the conference. The main topics included; Epilepsy prevalence in 4 selected Districts of Uganda by Dr. Joyce Kaducu a researcher from Gulu University, Patients Rights by Ms Regina Kamoga Country manager CHAIN Uganda, Boda Bodas, road accidents and epilepsy by Dr. J.B Mukasa a Neuro-Surgeon from Mulago Hospital, Epilepsy and the Nodding disease by Dr. Opar Bernard the head of the Nodding Syndrome National Task Force in Uganda

#### Participation.

The conference attracted persons with epilepsy, NGOs serving persons with epilepsy, professionals, researchers, policy makers, parents/guardians, health managers and other persons interested in fighting the stigma attached to epilepsy and improving the quality of life of persons with epilepsy in Uganda.

### 2.2.3. ESAU membership status as of december2012

	District Name	Membership Per Year						
		2004–2005	2006–2007	2008	2009	2010	2011	2012
1	Apac	123	175	55	172	182	50	172
2	Adjumani	0	0	101	30	187	100	246
3	Amuria	0	0	113	71	14	0	119
4	Arua	163	243	34	48	0	0	39
5	Bushenyi	159	152	1	3	3	0	19
6	Hoima	91	0	10	8	8	0	60
7	Jinja	263	0	33	29	40	12	134
8	Kabale	303	252	45	105	0	0	13
9	Ntungamo	295	38	2	52	2	0	16
10	Oyam	0	0	35	30	13	0	20
11	Soroti	619	341	74	103	73	0	14

12	Masindi	148	200	0	0	0	0	0
13	Tororo	80	47	0	0	0	0	0
14	Kampala	0	5	0	0	0	1	4
15	Serere	0	0	0	0	0	0	86
16	Sheema	0	0	0	0	0	0	17
17	Buhweju	0	0	0	0	0	0	6
18	Kaberamaido	0	0	58	136	9	0	8
19	Katakwi	0	0	13	115	19	60	48
20	Kumi	0	0	138	117	28	0	10
21	Luweero	208	64	95	31	20	11	96
22	Masaka	203	217	117	15	15	44	122
23	Mbarara	231	0	2	31	33	0	12
24	Mpigi	101	86	60	29	35	41	45
25	Moyo	20	215	122	182	50	0	33
26	Nakaseke	0	0	36	22	4	11	15
27	Gomba	0	0	0	0	0	0	4
28	Butambala	0	0	0	0	0	0	11
29	Lwengo	0	0	0	0	0	0	6
30	Kole	0	0	0	0	0	0	19
31	Kwania	0	0	0	0	0	0	4
32	Ngora	0	0	0	0	0	0	3
33	Bukkedea	0	0	0	0	0	0	13
34	Kalungu	0	0	0	0	0	0	22
35	Bukomansimbi	0	0	0	0	0	0	54
36	Kamuli	0	0	0	0	0	0	129
37	Sembabule	0	0	0	0	0	0	71
38	Maracha	0	0	0	0	0	0	70
		<b>3007</b>	<b>2035</b>	<b>1144</b>	<b>1329</b>	<b>735</b>	<b>330</b>	<b>1760</b>

Currently, ESAU has a membership of 10,340, who are registered members. In the year 2012, ESAU recruited 1,760 members of which 500 are People with Epilepsy, and the rest are parents, guardians, well-wishers or relatives of PWE. Compared to last year (2011), this year, there has been an increase in membership recruitment.

In the year 2012, ESAU continued to work closely with the 56 Faith Based Health Centers. Upon request, ESAU would buy epilepsy medications and send these health centers so that PWE could access regular and cheap medications according to their prescriptions.

ESAU provides continuous medical education to health workers from these units to influence their attitudes towards PWE. This arrangement has worked well and has provided a cheap alternative to medication for people with epilepsy; a supplement to the government medication which in most cases is irregular and unreliable.

### 2.2.5 Membership to International, National bodies and Corporate.

ESAU is a full member of NUDIPU and other international organisations and shall continue expanding her membership in the coming years. In the year 2012, membership has been paid to

Voices for Health Rights Organisations, International Alliance for Patients Organisations in Uganda, Uganda Alliance of Patients Organisations and International Bureau for Epilepsy. On the National scene, ESAU continues to work closely with all DPOs and hopes that PWE shall be served better in the coming years since NUDIPU accepted all DPOs to be represented on the governing Board.

## **2.3 ORGANIZATIONAL DEVELOPMENT**

ESAU provides continuous education to health workers, staff, volunteers, partners, local and district branch leaders from her different branches. The main objective of capacity building drives differ from section /group of people but mainly focuses on epilepsy care and management, record keeping, community mobilisation, resource mobilisation, advocacy and lobbying, report writing, financial management among others.

A number of capacity building activities were held this project period among which included the following:

### **2.3.1. Strategic Planning Workshop**

ESAU conducted a strategic planning workshop from 14<sup>th</sup>-15<sup>th</sup> August 2012 at Exotic Inn Bwaise. The workshop brought together 58 participants from different districts where ESAU operation. The workshop was facilitated by 2 consultants from Team Business Institute, supported by ESAU technical staff. The workshop focused on developing a five year strategic plan for the organization.

The strategic plan 2012 – 2017 which was developed in 2012 was a result of a participatory process that was informed by the results of the ESAU mid-term review as well as a workshop attended by carefully selected ESAU district and local branch leaders and secretariat staff.

The 2012 – 2017 ESAU strategic plan developed in the year 2012, therefore aims at consolidating the gains of the past 15 years of ESAU by focusing on strengthening district and local branches to become independent self sustaining community based organisations.


### **2.3.2 Training of Staff in project aspects**

One ESAU staff trained in Organizational Development for a post graduate Diploma at Uganda Management Institute, Kampala. She graduated in March 2012. This has enhanced the programme department in terms of capacity development and programming.

### **2.3.3 Annual retreat for Staff and BOD members.**

At the end of December, ESAU Organized the end of year Staff and BOD retreat to evaluate the success and challenges of ESAU. The retreat took place from the 14<sup>th</sup> -15<sup>th</sup> Dec 2012 at Comfort Hotel Entebbe. It was attended by 7 members of Staff and 6 members of the BOD.

#### **Objectives of the Retreat**

-  To assess the success and failures of ESAU as an Organization

- ✚ To strengthen and consolidate the achievements made by ESAU
- ✚ To forge the way forward for ESAU

### Major Issues Discussed

During the retreat, the BOD interacted with the staff. There was personal meditation and one on one discussion among staff and BOD respectively. This aimed at evaluating personal weaknesses, encourage effective communication between among all the parties and plan efficiently for the forth coming years.

The retreat helped each individual to self assess themselves in relation to their responsibilities in ESAU. Major focus was put on the sustainability of ESAU in the coming years with limited funding, forthcoming elections, fundraising and continuous epilepsy awareness and advocacy for improved services for PWE.

### 2.3.4 Esau occupies her own home

The ESAU has for the last 5 years worked tirelessly to secure its own office premises. This process started with the procurement of an acre of land in Wakiso Town Council in 2008. The actual construction started on 1<sup>st</sup> April 2011. ESAU planned to have an office building with enough space for its entire staff on the ground floor and a conference hall on the 1<sup>st</sup> floor.

Since 2008, each member of ESAU has been contributing 2000shs annually towards this project. Generous contributions were also received from the Norwegian Association of persons with epilepsy and the Danish Epilepsy association. The construction took 18 months and ESAU was able to occupy the building on 15<sup>th</sup> May 2012. The one storey building is located in Wakiso Town Council off the Kayunga – Kinoni – Wakiso Road on Block 275 Plot 695 in Gombe B Village 800m off the main Kampala – Hoima Highway.



**ESAU partners  
friends, neighbors  
and well wishers  
prepare for dinner  
during the official  
opening of the  
offices in Wakiso.**

ESAU is grateful to its board, staff members and friends who contributed to this project. The building was officially launched by the Chairperson of the Danish Epilepsy on 29<sup>th</sup> Oct 2012. The ceremony was attended by representatives of DPOS, partners, friends, neighbors and well wishers.

## **2.4 MONITORING AND SUPPORT SUPERVISION**

### **2.4.1. National BOD meetings**

ESAU has held 4 board meetings for the implementing period. The BOD meets to approve work plans and to discuss programmes to be implemented for the association as well. These were successful and the BOD looks forward to more meetings and opportunities to discuss organisation issues for effective running and project implementation.

### **2.4.2. Financial Monitoring by BOD**

Each month, the BOD chairperson and the Treasurer monitor the finances for the association. This has helped to keep the project on course and supported early implementation of activities for the project.

### **2.4.3. Project Monitoring Committee Meetings**



In the year 2012, two project monitoring committee meetings (PMC) were held. The PMC is a technical committee of ESAU and is composed of two BOD members and three ESAU Staff and the National Director. The main role of the committee is to oversee project implementation, progress and give technical guidance.

### **2.4.5. Annual Review meetings at National level**

#### **Introduction**

ESAU held a midterm review workshop on Monday 13<sup>th</sup> August 2012 at Exotic Inn Bwaise. Participants arrived on Sunday evening 12<sup>th</sup> August 2012. The workshop brought together 58 participants from different districts of ESAU's operation. The workshop was facilitated by 2 consultants from Team Business Institute, supported by 7 ESAU technical staff. During the workshop, the consultants presented the midterm review findings, which were conducted in 7 Districts of Jinja, Soroti, Serere, Oyam, Sheema, Masaka and Hoima

#### **Objectives of the consultancy**

-  Finalise the review of the final phase of the project
-  Present the preliminary report on the midterm review findings

#### **Objectives of the Review**

To determine if the project activities are beginning to bring about the change anticipated at the onset of the project.

#### **Scope of the Review**

1. Performance
2. Prevalence
3. Effectiveness
4. Efficiency
5. Impact
6. Sustainability

The review meeting report was developed and submitted to ESAU and the recommendations shall help ESAU in activity planning, budgeting and over all project implementation.

## **2.5 NETWORKING AND PARTNERSHIPS**

ESAU's mandate has always been to work with different organisations, alliances and networks with the main objective to create a better understanding about epilepsy to the different organisations with an aim to create linkages and synergies that can be built to better the lives of persons with epilepsy in any way possible.

### **2.5.1 African epilepsy congress.**

The first ever African Epilepsy Congress was held in Nairobi-Kenya from 21<sup>st</sup> to 23<sup>rd</sup> of May 2012. The Congress brought on board seasoned speakers from across the globe (North America, Asia, Europe, Africa, and Latin America) who brought with them a wealth of experience and expertise in the management and care of epilepsy.

Delegations at the congress included participants from Africa, Asia, Europe and Americas. In Africa in particular delegates were from Kenya, Senegal, Swaziland, Zambia, Cameroon, Malawi South Africa, North Sudan, Nigeria and Uganda. Uganda was represented by contingent of 12 delegates who included Persons with epilepsy, parents/guardians, and well-wishers of persons with epilepsy who were all staff and Board members of Epilepsy Support Association Uganda. The congress which lasted for 3 days was held at Crowne Plaza Hotel-Nairobi.

### **Main sessions at the congress:**

The Congress had a programme put together with a different theme each day. The main session of the congress begun on Day two and focused on proper diagnosis, management and special epilepsy populations while day two covered the management gap and co-morbidities as well as research in Africa. However, day three concentrated on primary healthcare and on the way forward in the African Region as will be illustrated in the reporting below.

### **2.5.2. NUDIPU general assembly**

ESAU participated in NUDIPU Annual General Assembly (AGM) that took place on Thursday 13<sup>th</sup> December 2012 at Pope Paul Memorial Hotel, Kabusu-Kampala. It was attended by ESAU BOD Chairman, Treasurer and National Director. Among the key issues discussed and resolutions made were NUDIPU Constitutional amendments.

The AGM made the following resolutions

- a) That all registered National DPOs shall be represented on the NUDIPU National BOD
- b) Two term limits was approved and this affects the board member not the position
- c) That National DPOs should be operational in at least more than 4 districts of Uganda
- d) That National DPOs and District Unions shall always meet their own transport costs and accommodation during AGMs and NUDIPU shall only cater for meals, mobilisation, pay for meeting venue and facilitators.

This representation of all National DPOs was a great achievement for ESAU for the year 2012 since ESAU has been at the centre of advocating for the same.

## **3.0 COUNSELING**

ESAU holds counselling sessions for persons with epilepsy, their parents, guardians and relatives at the Secretariat on a daily basis. This is done by ESAU staff at the Secretariat any individual interested in epilepsy information, epilepsy management, medication and other related information can always get it for free. In the year 2012, many parents of children with epilepsy, persons with epilepsy themselves, students from international universities came to consult ESAU on Epilepsy issues. ESAU has become a center of excellence on epilepsy consultations and 2011 saw a number of consultations carried out by ESAU staff to the tune of 220 consultations.

ESAU has created partnerships with 3 students at international universities interested in epilepsy. A joint proposal onto one of these universities was written to support persons with epilepsy though it did not pass through.

Mulago department of psychiatry has made it a point to refer patients for counseling and consultation as well, which has boosted the image of ESAU as a result. Many persons with epilepsy who have led meaningless lives through counselling having seen purpose in their lives now and have started taking medication.

## **2.6 FUNDRAISING AND RESOURCE MOBILISATION**

It has been a year of learning and discovery for the fundraising and resource mobilisation for ESAU. Since fundraising is a gradual process that need patience, ESAU has been on the lookout in the year 2012 to for possible funding opportunities locally, nationally and internationally. Some projects have been submitted and funded, some were rejected, others and still in the pipeline to be submitted while some were submitted and ESAU never got the reply.

### **2.6.1 Mini Project for Northern Uganda (Gulu Project)**

ESAU through her partners has secured some funding from Disabled People's Organization of Denmark (DPOD) to implement a two year project in Acholi sub region covering the 4 districts of Amuru, Gulu, Pader and Kitgum. ESAU intends to form 12 Psycho social support groups for people with epilepsy with democratically elected leadership. This project is anticipated to begin early January 2013 with its field office in Gulu. The project shall focus on massive sensitization of the communities and institutions of higher learning through forum theatre and mobilizing people with epilepsy.

Forum Theatre is an interactive form of theatre that encourages audience interaction and explores different options for dealing with a problem or issue and it is often used by socially excluded and disempowered groups. Forum Theatre was identified by ESAU as a tool of providing accurate information on epilepsy as a way of Sensitizing young professionals and community members on epilepsy in order to enhance a better understanding of epilepsy so that they can provide adequate support to people with epilepsy.

The project shall be composed of 70 forum theatre performances in total where 50 of them shall be in the communities and 20 performances in institutions. The community performances in the communities will be conducted in the local language (Luo) so that people can understand the messages in the play while the ones in institutions shall be conducted in English.

In this project, ESAU target is to reach 1,000 People with Epilepsy, 10,000 parents of people with epilepsy, 6,000 community members from 50 communities, 4000 professionals & 50 district leaders (politicians, civil servants, nurses & students) reached with epilepsy information through forum theatre and 50% incorporate epilepsy issues in their planning and ESAU also intends to established partnerships with the nodding disease task force in Pader and Kitgum.

#### **2.5.4. ESAU/SIDA/VHR Maternal Health Project**

In August 2011, ESAU was awarded funding of 230 million Ugandan shillings for 3 years by the Swedish Development Agency, through a coalition of Orgnasiations of Voices for health (VHR). The project was to be implemented in the two districts of Sheema and Soroti in the Subcounties of Shuuku and Tubur respectively. In the year 2012, ESAU continued linking maternal health issues with epilepsy and this created an opportunity for better advocacy, while contributing to the reduction of maternal mortality in Uganda especially in the districts of Sheema and Soroti.

##### **Project Objectives**

1. To empower communities to demand for quality maternal, sexual and reproductive health services.
2. To promote access and utilization of maternal, sexual and reproductive health services among communities.
3. To increase capacity of communities/groups to monitor and hold key duty bearers accountable for delivery of maternal sexual and reproductive health services.
4. To strengthen institutional capacity of VHR for effective implementation of quality MSRH program

##### **Achievements**

- ✚ 40 Community maternal health advocates and 2 focal persons responsible for the maternal health project were retrained in maternal health and reaching out to the communities in the 2 districts with information on maternal health. Communities now more appreciative of the plight of mothers and supportive of them.
- ✚ Health Unit Management Committees (HUMCs) were facilitated to meet 8 times in the year 2012 in the Subcounties of Shuuku and Tubur. This has made community concerns and health workers issues to be addressed swiftly as well as timely response to concerns from suggestion boxes which gives citizens a sense of social accountability.
- ✚ 96 outreaches for maternal health supported by the project. This has led to an integration of maternal health in the normal outreaches conducted by the health units. Communities aware about their reproductive health rights as a result.
- ✚ Partnerships with traditional birth attendants and other maternal health service providers in the 2 districts were established with to create better synergies and achievements of the goals of the project.
- ✚ 8 Radio talk shows were held to talk about the maternal health project, the different mandates of each of the organisations and the expectations of the project from the communities. ESAU used such opportunities to raise awareness about epilepsy and provide accurate information to demystify the myths surrounding the condition.



## 2.5.5 IAPO African Members' Grant

### Over View

IAPO members in the African region met to develop an action plan in South Africa in April 2011. To support the implementation of this action plan, IAPO requested for applications from member organisations in the African region to apply for funds to undertake small activities which support the objectives of the action plan.

In the year 2012, ESAU applied for the grant of 700,000sh and was successful in support of a one off activity in line with the action plan. This activity aimed at sensitizing leaders of patient's organisations about patients providing their own medications due to drug stock outs and inadequate supply in the government health facilities.

Using this activity based grant, ESAU held a one day meeting of 20 partners and shared with them the successes, achievements, experiences, implementation and advantages of running a community drug bank. Participants were given different ways of ensuring regular accessibility of cheap medications to the patients they represent in times of drug stock outs in public healthcentres. Members appreciated the model and pledged to copy it in order to serve better the patients they represent

## 2.5.6 Support to Branch Proposal writing

In the year 2012, ESAU Secretariat technically supported three district branches of Nakaseke, Soroti and Jinja to develop and submit convincing applications for funding. Masaka applied for the disability grant, Jinja applied for funding form NUDIPU HIV Project while Soroti applied to IDF. By the end of the year 2012, all the applications had been submitted waiting for reply. In the year 2013, ESAU pledges to support more of her branches in proposal developing so that they are able to sustain themselves.




### Grant writing status for the Organisation

NAME OF GRANT MAKER	SUBMITTED	STATUS
DRF 1	Yes	Not Granted
IBE (School Epilepsy Clubs)	Yes	Granted
DRF 2	Yes	Waiting for response
IAPO Member Grant (Community Drug Banks)	Yes	Granted
IDF 1	Yes	Not Granted
Mini Project (Youth Speak Out)	Yes	Waiting for response
IDF 2	Yes	Waiting for response
Mini Project (Northern Uganda)	Yes	Granted

## 3.0 FINANCE

### 3.1 Esau's Income For 2010

In the year 2012, ESAU's received income from the following sources;

-  Danish Epilepsy Association (DEA)-Mini Project for Northern Uganda
-  International Bureau of Epilepsy (IBE)-Goat Rearing Project
-  SIDA-VHR -Maternal Health Project

- ✚ International Bureau of Epilepsy (IBE)-School Epilepsy Clubs Project
- ✚ IAPO Member Grant (Community Drug Banks)
- ✚ Membership fees

#### 4.0 ACHIEVEMENTS

- ✚ ESAU finalized the construction of her offices in Wakiso and was officially launched on 29<sup>th</sup> December 2012. The building currently hosts ESAU Secretariate.
- ✚ ESAU managed to develop 8 National Project proposals and submitted all of them. Three were granted, three still waiting for response while two were not funded.
- ✚ Successfully conducted a National Advocacy Epilepsy Conference that brought to light the plight of PWE.
- ✚ Developed a 5 year strategic plan after a well attended midterm review that was attended by representatives of all ESAU branches.
- ✚ Increased membership to the association. More people have joined the association as a result of increased awareness raising compared to last year (2011)
- ✚ Counseling and guidance services were provided as a result, parents and clients were happy due to reduced negative attitudes in their communities
- ✚ 3 district branches were supported by the secretariat to develop and submit applications for their respective branches for funding.
- ✚ ESAU continued supporting faith based health centres to run community drug banks and this enabled PWE to access regular and cheap epilepsy medications.
- ✚ ESAU managed to liaise with the National Nodding syndrome task force and this linkage has made PWE access epilepsy medications which for long the Ministry of Health has not been stocking.

#### 5.0 CHALLENGES

- ✚ Networking with developmental organizations at district/sub county level like NUDIPU, NOWUDU and the CDOs is still a challenge for ESAU membership especially at district and sub county level.
- ✚ Limited and un timely disbursement of medicine (AEDs) at health centres as well as long distances travelled by some of the Persons with epilepsy still poses a challenge to the association especially as the numbers are increasing.
- ✚ ESAU still has to mobilise funds to fully implement her activities through out her districts of operation. With the creation of new districts, there has been more branches formed. However, some of these branches are not facilitated and there are no sufficient funds to cover such areas.
- ✚ The reporting for Health workers is not regular and prompt. It is also mixed with other illnesses making it hard to follow up on data related to Persons with Epilepsy in terms of attendance for clinics which has created difficulty in tracking epilepsy prevalence based on such statistics and has a direct effect on planning.
- ✚ No platforms and fundraising structures were in existence to build from. A lot of the fundraising drives required starting the different initiatives from scratch.

## 6.0 FUTURE PLANS FOR THE ASSOCIATION

- ✚ Have fundraising plans in place for this year's fundraising efforts and start a cultivation drive for supporters of ESAU
- ✚ Search and write more grant proposals to international and bi-lateral donors.
- ✚ ESAU plans to continue mobilising persons with epilepsy and sensitising communities so as to increase membership to the association.
- ✚ Continued awareness raising, among district officials in the districts of operation, civil society leaders, community development assistants, secondary and primary school teachers, students, health workers and others on issues concerning epilepsy.
- ✚ Continued advocacy and lobbying at national, district and sub county level and imparting of advocacy and lobbying skills among BOD members, PWE leaders and volunteers.
- ✚ Improving fundraising strategies and thereby make Esau's activities more sustainable; proposals for funding as one of the alternative funding resources as well as from membership.
- ✚ Continued monitoring and evaluation of all organizational programmes.
- ✚ Popularize epilepsy through forum theatre especially in institutions of higher learning.

## 7.0. Conclusion

ESAU finds 2012 a fairly successful year though surrounded with several financial challenges. However, the organisation pledges to continue fundraising for more funds and cultivating relationships with donors. Branches will be supported by staff to fundraise for funding for their activities. ESAU will also join partnerships, networks and alliances to popularize epilepsy and the plight of people living with epilepsy.

## 4.0 APPENDICIES

### Board of Directors

1.	Odongo	Andrew	Chairperson-	Soroti
2.	Lukanda	Jane	Board Member-	Jinja
3.	Nakidde	Juliet	Treasurer-	Nakaseke
4.	Ebong	Anthony	Secretary-	Apac
5.	Sabiti	Peter	Publicity Secretary-	Kabale
6.	Namugenyi	Gorreth	Board Member-	Masaka
7.	Kebigombe	Edith	Board Member-	Ntungamo

### ESAU Staff

1. Mugarura Augustine	National Director
2. Sarah Nekesa	Accountant
3. Engole Justine	Project Officer-Organisational Development
4. Ndyahika Dickson	Advocacy Officer
5. Ocoto William	Project Officer-Mini Project Gulu
5. Kyarisiima Clare	Administrative Assistant
7. Ochan Paul	Logistics officer/Driver

### Support staff

1. Mariam Namusoke.
3. Mulengera George.