



SWAZILAND EPILEPSY ORGANIZATION

THIRD QUARTER PARLIAMENT REPORT:

2016/17



BACKGROUND INFORMATION

Swaziland Epilepsy Organisation is a Swazi registered organisation which is registered under the Swaziland Companies Act of 2010. Swaziland Epilepsy Organization coordinates the establishment of Epilepsy Support Groups to mobilize at a community level. The association strengthens advocacy issues surrounding epilepsy and initiates capacity building, skills and the sharing of information through dissemination to all citizens.

According to the World Health Organisation Fact Sheet (2016), Epilepsy is a chronic disorder of the brain that affects people worldwide. It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized), and are sometimes accompanied by loss of consciousness and control of bowel or bladder function. Seizure episodes are a result of excessive electrical discharges in a group of brain cells. Different parts of the brain can be the site of such discharges. Seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions. Seizures can also vary in frequency, from less than 1 per year to several per day.

One seizure does not signify epilepsy (up to 10% of people worldwide have one seizure during their lifetime). Epilepsy is defined as having 2 or more unprovoked seizures. Epilepsy is one of the world's oldest recognized conditions, with written records dating back to 4000 BC. Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma continues in many countries today and can impact on the quality of life for people with the disorder and their families.

Epilepsy is one of the most common serious neurological diseases in childhood. The incidence of epilepsy is slightly higher in male patients with epilepsy. Patients with epilepsy commonly have multiple psychological, psychiatric and social problems due to their illness and also due to

medication. There is significant psychological and social impact of epilepsy. Epilepsy is associated with increased mortality, including increased risk of sudden unexpected death. Epilepsy can also result in morbidity which may be physical, occurring directly from seizures. The patients can also have cognitive delay, speech difficulties, language difficulties or learning disabilities. Epilepsy can also result in aggressive behaviour or psychosocial issues. Patients frequently have poor knowledge of epilepsy. Thus, they are more prone to having low self-esteem.

PREVALENCE OF EPILEPSY

WHO estimates that there are 50 million people currently living with epilepsy worldwide. Out of the 50 million, 40 million receive no treatment when, for only a small amount of money, 70% of these could lead seizure-free lives. The estimated proportion of the general population with active epilepsy (i.e. continuing seizures or with the need for treatment) at a given time is between 4 and 10 per 1000 people. However, some studies in low - and middle - income countries suggest that the proportion is much higher, between 7 and 14 per 1000 people.

Globally, an estimated 2.4 million people are diagnosed with epilepsy each year. In high-income countries, annual new cases are between 30 and 50 per 100 000 people in the general population. In low - and middle - income countries, this figure can be up to two times higher. This is likely due to the increased risk of endemic conditions such as malaria or neurocysticercosis; the higher incidence of road traffic injuries; birth-related injuries; and variations in medical infrastructure, availability of preventative health programmes and accessible care. Close to 80% of people with epilepsy live in low- and middle-income countries which Swaziland is a part of.

WHO also estimates that of the 10 million people in Africa who live with epilepsy, 80% or eight million are not treated with readily available modern drugs. Thanks to modern medicine, most of

the causes of symptomatic epilepsy in our region can be greatly reduced by prevention and treatment. Yet, epilepsy continues to take its toll among our people causing impaired physical, psychological and social functioning of those affected, and equally serious psychological, social and economic consequences for their families. Worse still, people with epilepsy, sometimes along with their family members, are often stigmatized. This stigmatization generates a hidden burden, which discourages patients from seeking the diagnosis and care they need and deserve. The difference between the need for treatment and the treatment dispensed is termed the “treatment gap”. There are no treatment gap figures yet available for Swaziland but in neighbouring South Africa the gap is 90%. Another fallout of stigmatization is the discrimination, as people who experience seizures but are able to work are unemployed; and many who are able to find employment are underemployed.

EPILEPSY IN SWAZILAND

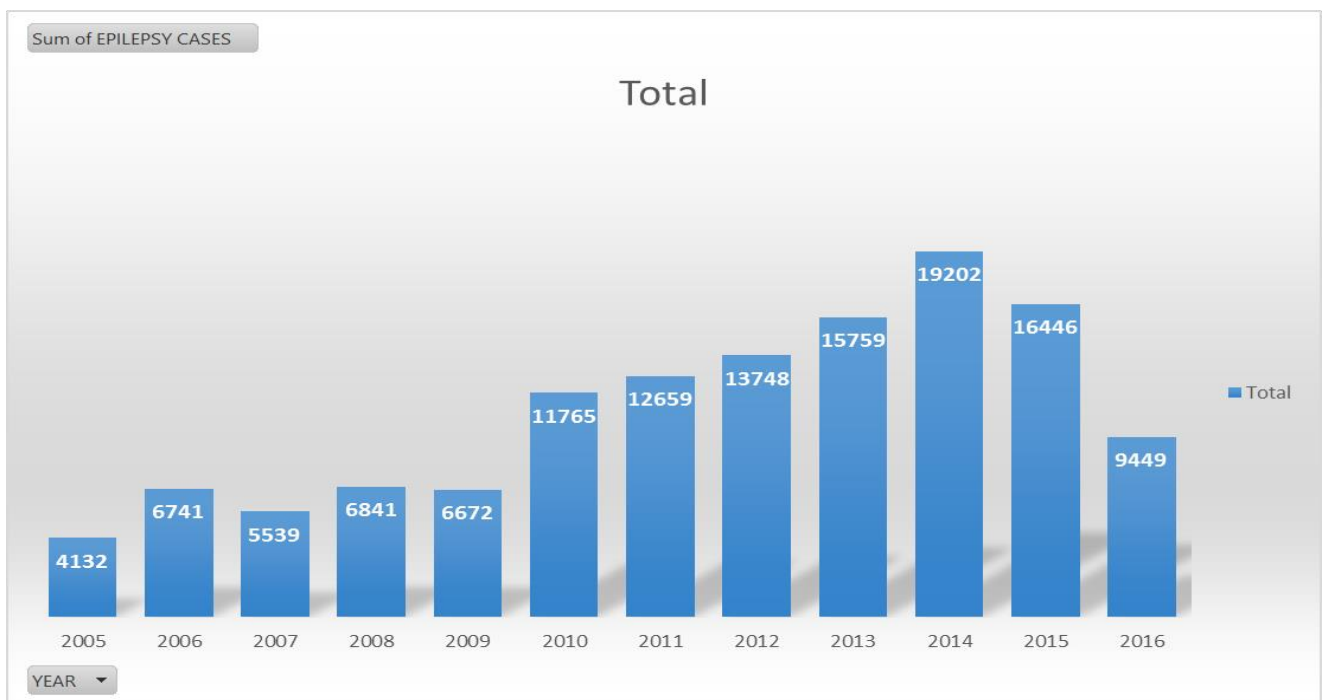
The Swaziland Epilepsy Organization (SEO) and the Ministry of Health are making enormous efforts in promoting the recognition of Epilepsy, its diagnosis and management. However, there are underlying issues: There is no permanent neurologist in Swaziland to help diagnose epilepsy. Diagnosis is made by hospital physicians and general physicians as well as nurses. There is only one EEG machine in Swaziland which was donated in September 2016 to the SEO by a UK Clinical Neurophysiologist. This particular diagnosis machine was set up in the Mbabane Government Hospital Psychiatric Hospital where two local nurse were trained by UK doctors on the technicalities of using the TeleEEG to enhance epilepsy diagnosis in Swaziland.

Three free antiepileptic drugs are issued in Swaziland: sodium valproate, carbamazepine and phenobarbitone. These are good drugs however there are some problems with these medications: Sodium valproate can increase the risk of birth defects; carbamazepine makes absence and

myoclonic epilepsy worse; phenobarbitone can make absence epilepsy worse. The idiosyncrasies of these drugs are not well known to prescribing clinicians in Swaziland. Knowing the type of epilepsy a patient has a clinician can tailor the most suitable antiepileptic drugs. The EEG can help to differentiate the type of epilepsy.

EPILEPSY CASES IN SWAZILAND

Figure 1 – Reported Epilepsy cases from the year 2005 to mid-2016



Source: The data used in this graphical representation was obtained from the Health Management Information System (HMIS)

Figure 1 above is a graphical representation of reported epilepsy cases from the year 2005 to mid-2016. Though there are fluctuations, the figure show a steady increase of reported epilepsy from **4, 132** in 2005 to **16, 446** in 2015. The year 2014 recorded the highest number epilepsy cases at **19, 202**. It is also worth noting that the data was obtained mid-2016, thus, the number of

reported cases as shown in the graph for the year 2016 are is conclusive. The figure may be higher.

The general increase in reported epilepsy cases from the year 2005 is directly related to the time when the organization started engaging in activities that sensitize and educate people about epilepsy. As a result, people who may not have been aware of the condition and that it can be managed with the right treatment – started going to hospitals and clinics for medical attention. The slight decline in reported cases that is sometimes witnessed can be due to a number of factors. The death of people with epilepsy is one of them. Some people may turn to private clinics for further medical assistance due to the deficiencies public health institutions have in Swaziland.

There are five (5) public major hospitals and four (4) health centres dealing with epilepsy in Swaziland. The graph, therefore, reflects those numbers reported in these health facilities. It does not take into account those people attending private clinics and hospitals.

THE SWAZILAND EPILEPSY ORGANIZATION'S MANDATE

Its goals include but not limited to the following:

- ❖ Providing a platform for general epilepsy awareness and assist Departments of Health in the development of National Epilepsy Treatment Strategies
- ❖ Increasing public and professional awareness of epilepsy as a universal, treatable brain disorder
- ❖ Identifying and mitigating the needs of people living with epilepsy, on a national and regional basis

- ❖ Encouraging Government to address the needs of people living with epilepsy including awareness, education, diagnosis, treatment, aftercare services and general welfare.

1. Vision, Mission, Values

1.1. Vision statement

“The Swaziland Epilepsy Organization strives to develop and promote areas of intervention for the effective treatment and social integration of people afflicted and affected by epilepsy, while enriching the livelihood of the Swazi nation”.

1.2. Mission statement

“To improve the accessibility of treatment, services and prevention of epilepsy in the Kingdom of Eswatini”.

1.3. Shared Values

SEO’s ethics and values are a philosophy against which decisions are based in pursuit of the Organization’s excellence. These are:

- ❖ *Respect*
- ❖ *Integrity*
- ❖ *Accessibility*
- ❖ *Transparency*
- ❖ *Accountability*
- ❖ *Promoting unity in diversity*

2. Operational Strategy

Swaziland Epilepsy Organization has adopted five thematic areas of intervention aimed at steering the Organization strategically towards its desired vision, these strategic focus areas are:

2.1 Advocacy and awareness with a main emphasis on information dissemination, protection of legal rights of people living with epilepsy especially in the workplace and workplace awareness program.

2.2. Impact mitigation which focuses on health provision and livelihood sustenance.

2.3. Resource mobilization which entails the creation of a diverse revenue base with the objective of driving the Organization away from donor dependency syndrome but towards financial independence or sustainability through the implementation of events and community based projects and other investment options.

2.4. Capacity building which addresses the training needs of staff and support groups, the development of internal policies and exploration of international relations.

2.5. Capital projects which involves the Organization's major goal, the construction of an epilepsy clinic and centre.

PROGRAMATIC PERFORMANCE

Table 1

	Column Labels		
	OFFICE VISITS	TELEPHONE CALLS	Grand Total
Count of FREQUENCY	58	63	121

Figure 2

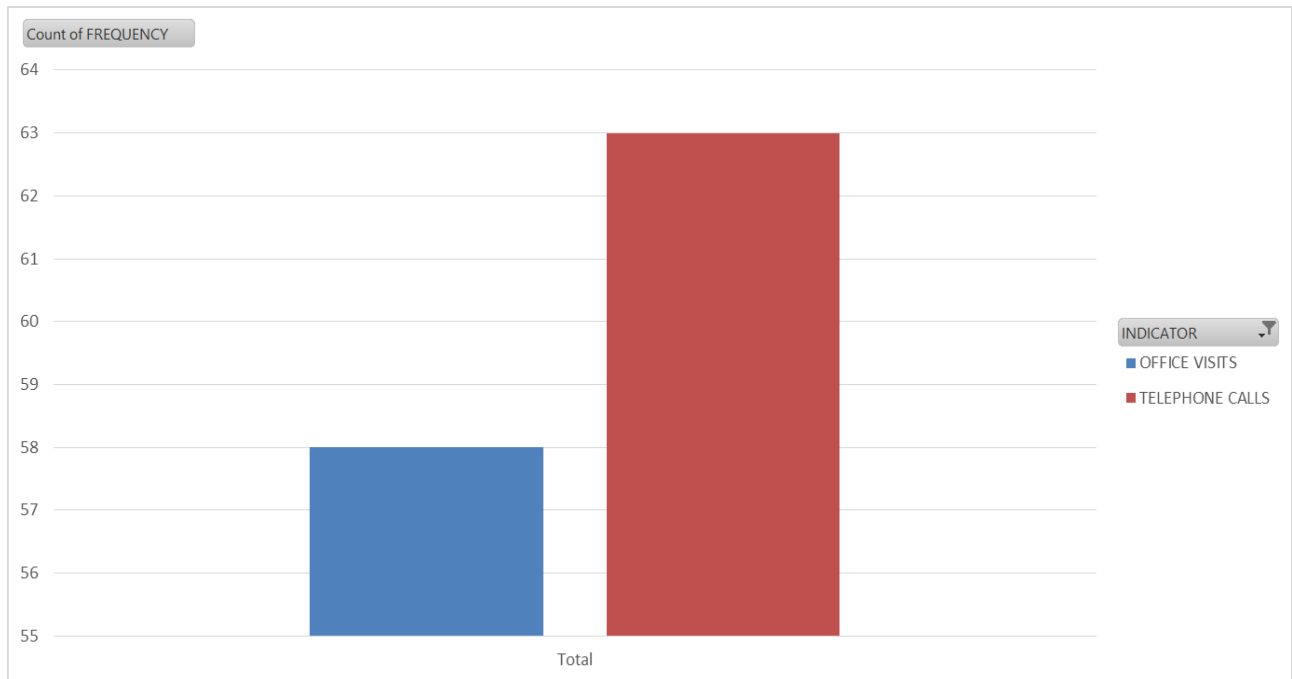


Figure 2 and the table 1 above have been extracted from the organization’s checklist and database reporting tool. It shows that in the 3rd quarter (Oct – Dec), the organization received 68 telephone calls related to epilepsy health issues from the general public and 58 office visits (Clients Volume) from the public enquiring about the services the organization provides or seeking assistance with economic and health issues related to epilepsy. The increase in these figures from the previous quarter maybe caused by TeleEEG appointments. The public would call the office to request an EEG appointment with the Psychiatric nurse at the Mbabane Government Hospital. Others would personally visit the office to make the appointment.

THE TeleEEG STATISTICS

Since its establishment in July 2016, 78 patients have had EEGs carried out using the system.

Table 2

AGE GROUP	MALE	FEMALE
0 – 5	6	10
6 - 11	5	5
12 - 18	9	5
19 and above	15	18
TOTAL	35	38

Source: Mbabane Government Hospital Psychiatric Unit (November, 2016)

From the above table, one can see that there were more females than males who have had their EEG’s carried from July to November. There were 38 females and 45 males, respectively. There were also a high number of patients between the age group 19 and above, both sexes combined. The EEG tests are carried once a week (Tuesday only). EEG appointments are made prior through the office or directly with the nurse at Mbabane Government Hospital Psychiatric Unit.

This single TeleEEG service can cover the EEG requirements for a population of around 500,000. Therefore to fully cover the population of Swaziland of 1.25 million people, two more TeleEEG services would need to be installed.

Local staff are in further need of training on epilepsy and EEG. Local clinicians presently employed in diagnosing epilepsy would benefit from a thorough knowledge of the clinical manifestations of epilepsy, investigations including EEG and management. Epilepsy management would include knowledge of the indication and side effects of commonly prescribed antiepileptic drugs. Feedback given in TeleEEG reports by Dr. Steve Coates can help with this training.

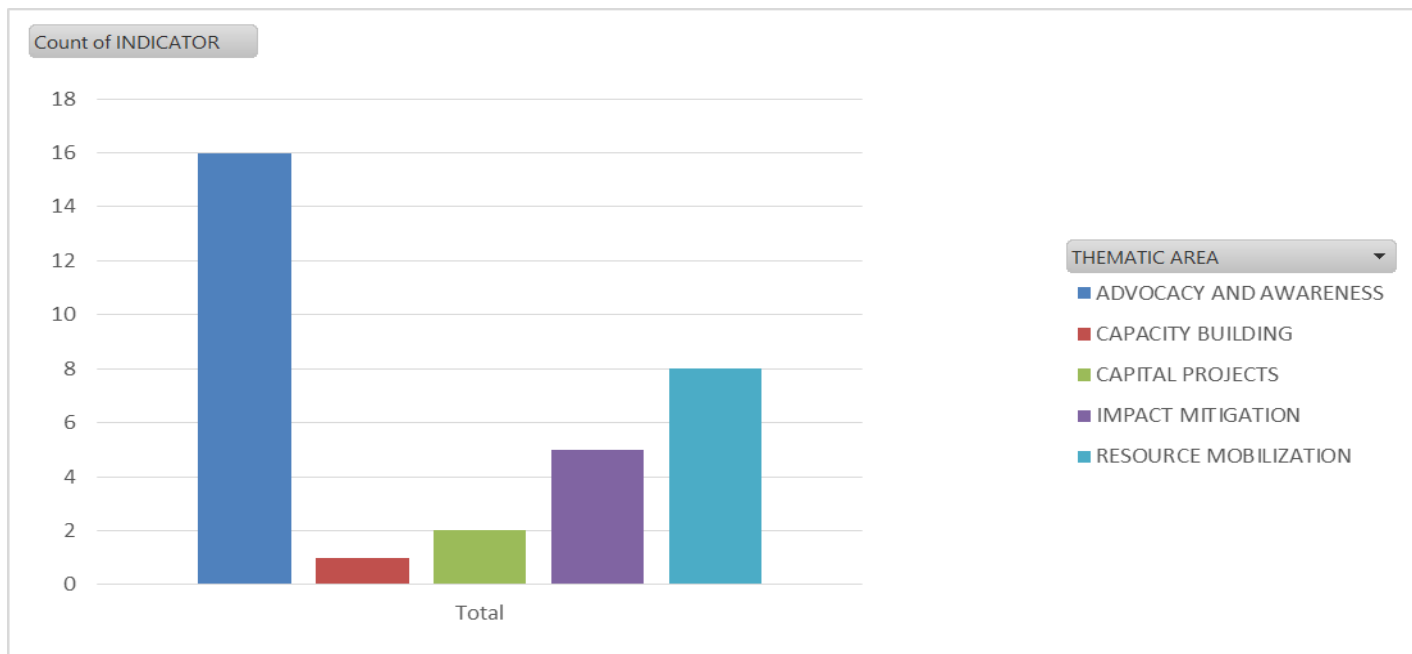
Undoubtedly, the use of sophisticated epilepsy diagnosis tools like the TeleEEG machine is a way forward for African countries who lack EEG equipment and qualified EEG interpreters.

HIGHLIGHTS

Table 3

Column Labels	ADVOCACY AND AWARENESS	CAPACITY BUILDING	CAPITAL PROJECTS	IMPACT MITIGATION	RESOURCE MOBILIZATION	Grand Total
Count of INDICATOR	16	1	2	5	8	32

Figure 3 – Bar graph representation of summary of activities under each thematic area



Source: SEO checklist and database

1. **Advocacy and Awareness** - the organization undertook 16 advocacy and awareness activities. These are:

- ❖ Community Outreach - Mental Health Day – In October, the SEO participated in the commemoration of the Mental Health Day at Mafutseni Inkhundla organized by the

National Psychiatric Referral Hospital in collaboration with the Ministry of Health, under the theme 'Dignity in Mental Health: Psychological First Aid (PFA) and Mental Health Services for all.' This was an opportunity for the organization to raise awareness and educate people of Mafutseni about epilepsy. The organization was able to reach 80 people, amongst which were students from neighboring schools, men and women. It was the observation of the officers present that people from the area have vague knowledge of epilepsy. This includes epilepsy first aid, myths surrounding epilepsy as well as the treatment options available for those people with epilepsy in Swaziland. During the educational talks, officers made sure to focus mainly on those areas.

The organization also distributed IEC material during the event. These include 80 flyers talking about the TeleEEG machine and 80 pamphlets on Epilepsy and Pregnancy. Furthermore, 200 more pamphlets on Epilepsy and Pregnancy were given to the National Psychiatric Referral Hospital to distribute to their patients.

- ❖ Digital Story Telling - The organization submitted a Digital Story to COMDIS-HSD to be showcased to the public. The Digital Story was about a woman at Sicelwini that received a donation of E5000 from the organization whose son is living with epilepsy and other disabilities. The story was about the challenges one face when living with someone with epilepsy as well as how the help they received from the organization has changes their lives.

With great focus on HIV/AIDS and TB in Swaziland, non-communicable diseases (NCDs), disabilities, and other social issues are often underreported and neglected by health care services and international partners in regards to access to care,

- rehabilitation, and psychological support. This initiative by the COMDIS-HSD is used to address myths about certain NCDs (e.g. impotence among men with diabetes), tackle the fears and stigma that one might have around a condition or disability (i.e bipolar disorder), and raise awareness for the type of care and treatment needed for certain conditions (e.g. there's only one psychiatrist in the entire country to treat mental health conditions).
- ❖ Newspaper articles – the organization wrote a press statement titled “Epilepsy in the SADC region: Bridging the gap?” which was published by the Swazi Observer. The Statement was a strategy to lobby for support of epilepsy from governments and other stakeholders in the SADC region. The press statement was released during the week where Health Ministers from SADC countries were meeting in the country. The statement highlighted the plight of people with epilepsy in the SADC relating to stigma, discrimination and access to treatment. It also urged SADC member states to consider including epilepsy in the agenda of the next SADC meeting. The press statement was well received by the African Epilepsy Forum. Other members were also encouraged to emulate actions of the SEO in the fight against epilepsy in Africa. The SEO also published information about the International Epilepsy Day Art Competition by the IBE for the public to see in the both the Times of Swaziland and the Swazi Observer. The article was inviting members of the public to join the competition by submitting any form artwork in commemoration of the International Epilepsy Day under the theme “Putting Epilepsy in the Picture.” The competition was open to all ages. The International Epilepsy Day in on the 13th of February, 2017.

- Lastly, in November the organization invited all media houses to a breakfast meeting held at the La Casserole restaurant. The purpose of the meeting was for the media to meet the visiting doctors from the UK who had come to provide further training to the two local nurses that operate the TeleEEG machine at the Mbabane Government Hospital. The nurses were trained on the technical skills of operating the EEG machines. Dr. Anne Clarke, said that a lot of people in the country were not aware of the symptoms of epilepsy. However, the nation was lucky to have an organization that takes care of the welfare of people with epilepsy in the country.
- ❖ Media Programmes – the National Director was on radio (SBIS 1) programme called “Letisematseni” talking epilepsy and driving. If you drive, one immediate effect of having a seizure is that you have to stop driving. This is true for all types of seizures, and whether you have a diagnosis of epilepsy or not. For many people, this can have a big impact on their life and it may be very difficult or upsetting. It’s important to stop driving when you’ve had a seizure because a seizure could affect your ability to drive safely.
 - ❖ Lobbying – the SEO continues to be an active participant in the African Epilepsy Forum. The National Director is in constant engagement with representatives from other epilepsy organizations in Africa. The SEO is lobbying for epilepsy to be made a health priority in the African region in general and the SADC region in particular. The SEO was assigned with the task of drafting a petition to be delivered at the SADC Headquarters in Gaborone, Botswana. A petition was drafted by the SEO and was submitted to the forum to go through it and make changes where necessary. The SEO has definitely become a big player in epilepsy discussions amongst its

- counterpart. The opinions and ideas the organization are heard and further implemented.
- ❖ Community outreach – The SEO participated in a Charity event organized by the Farai Foundation whose patron is HRH Prince Majaha at Ekwetsembeni Special School in commemoration of the International Disability Day. The organization was given a time slot to make a short presentation to the public. The presentation highlighted the mandate of the SEO and also encouraged the public to visit our offices for more information. At the event, the organization distributed 60 pamphlets about Epilepsy and Pregnancy and 60 other about the TeleEEG machine.
 - ❖ Community outreach - The organization visited Mkhuzweni Health Centre at Buhleni in the Hhohho Region. The purpose of the visit was to collect data and talk to the epilepsy support group at the health centre about epilepsy and issues surrounding it. The organization successfully had an hour discussion with the group. The group voiced out numerous concerns amongst which was the shortage of anti-epileptic drugs in the health centres. The groups also voiced out their desire to have an EEG machine set up closer to Buhleni because going to Mbabane for an EEG test was just not practical for them. The groups is characterized by unemployment. The organization in a process of setting up income generating projects for the support group to sustain their livelihood. The Mkhuzweni Health Centres has on average 60 reported cases of epilepsy whereas Herefords clinic, Mangwaneni clinic, Ndwabangeni Clinic have 10, 25, 20 reported cases of epilepsy respectively.
 - ❖ African Epilepsy Congress Abstract – the SEO submitted an abstract for a poster titled “The first TeleEEG service for the diagnosis of epilepsy in Swaziland – a way

forward for Africa?” to the International League Against Epilepsy (ILAE) to consider for presentation at African Epilepsy Congress in Dakar, Senegal in May 2017. This is great opportunity for the organization to present itself on an international stage – a move that could bring great opportunities for the country in the treatment and management of epilepsy.

- ❖ Tikhuba House Construction – the organization has come to the rescue of a 10 year old boy from Tikhuba who has been living with epilepsy from a very young age. The organization elected to build one room flat for the boy and his 50 year old mother who are living under a stick and mud shelter with its roof curving in. This initiative is expected to be completed within a timeframe of 6 months commencing the September 2016.

2. **Capacity building** - under this thematic area the organization was only able to undertake one activity:

- ❖ TeleEEG machine training - following the donation of the TeleEEG machine stationed at the Mbabane Government Hospital Psychiatric Unit in September, as it was promised, a Doctor and a Nurse from the UK were in the country in November to train the two (2) local nurses who are operating the TeleEEG machine at the Hospital. The nurses were trained on the technical aspects of using the TeleEEG to get better readings. The training was done over a period of 3 days. During that the doctor was able to see 18 epilepsy patients at the Mbabane Government Hospital. Dr. Clarke said the equipment was working very well and the nurses have become technically confident. The EEG has to be utilized by patients who were referred for query of an epilepsy diagnosis.

3. **Capital projects** – in its pursuit of the mission of improving the accessibility of treatment, services and prevention of epilepsy in the Kingdom of Swaziland - the SEO submitted a proposal to the European Union (EU) seeking E5 million funding to finance the building of the Epilepsy Centre at Sikhuphe near the King Mswati III International Airport. The centre will comprise a state-of-the-art Epilepsy Treatment Clinic and Administration offices to house the SEO executive and the Agribusiness Admin Division. Furthermore, the organization submitted a proposal to Montigny Timber Company for the provision of timber material to be used in the construction of the epilepsy centre, mainly the area where there will be stalls used to showcase the handcraft products made by people with epilepsy all over Swaziland to potential buyers.
4. **Impact Mitigation** – under this thematic area the organization was able to undertake five (5) activities:
- ❖ Community outreach - SEO officers visited the Luve community to check on progress made on the handcraft project funded by the International Bureau for Epilepsy (IBE) that is carried out by the youth of the area. The organization took pictures of the work done to report back to the IBE. Pieces of handicraft have been completed and some of them are ready for sale. The youth of the area have been equipped with the skills that will enable them to sustain the project and also generate income from it. The goal of the project was to empower the youth with the necessary skills to make a living as was to counter the problems of youth unemployment in the country more especially among people with epilepsy. However, there were complaints from some members of the support group who are disabled (hand injuries due to burn wounds) that they are

- not able to fully participate in the project. They have requested the organization to find alternative ways to cater for their disability so that they can also be empowered.
- ❖ Food Hampers – the organization responded to a call from a community member at Luve about a woman that is suffering from severe epilepsy seizures. The woman is unemployed and lives with her daughter in law whom is also unemployed because she has to take care of the sickly mother in law. The son of the mother is also bed-ridden in hospital. The family has no source of income, they survive on handouts from neighbors. This is just one of the many people afflicted by epilepsy trapped in the cycle of poverty because of unemployment.
- The woman is on AEDs must take them with a full stomach. The organization managed buy groceries for the struggling family amongst which were chicken portions, Sugar and Bread. Another challenges faced by many people with epilepsy at Luve is access to treatment. The nearest clinic is 15 KM away from the small town. More often than not they walk to and from the clinic. Thus they can be discouraged to attend the clinic when it's time to refill the medication.
- ❖ School fees paid – the organization fulfilled its obligation of paying school fees for a form 4 student with epilepsy at Swazi National High School.
 - ❖ School Uniform Donated - The organization donated school uniforms to 6 vulnerable students from Cedusizi Primary School between the ages 11-13 years old. Five of them are in Grade 4 and only one is in Grade 5. Amongst the group were 3 boys and 3 girls. The girls received a tunic and a jersey and the boys received jerseys only. All of them were supposed to receive a full school uniform however, due to the challenges faced with the supplier only jerseys and tunics were supplied. There boys were

supposed to receive jerseys, shirts, trousers, and shoes and the girls were supposed to receive tunics, jerseys and shoes. The organization apologized for the delay and also promised to donate the remaining uniform in January.

- ❖ Dairy Farming – in 2010, the Thulwane community support group initiated an agri-business program which enhance their socio-economic livelihood for self-sustenance. This is supported by the WHO resolution endorsed in Geneva last year (2016), which calls for member states to initiate programs that will address the social ills faced by vulnerable people with epilepsy and disabilities, with a particular focus on women and children since they are the most vulnerable when afflicted by the neurological disorder. The support groups consists of 13 members most of whom are women. The engage in crop farming and dairy farming.

The project faced numerous challenges due to the drought situation which was prevalent last year in the country. The dry season led to poor crop and milk production. Revenue from this activities declined. The project which was self-sustainable all along was not able to sustain itself. The organization had to fork out money to buy hay bays to feed the dairy cows. Unfortunately, one of the 7 cows and its calf succumbed to death due starvation and some other illness. The organization tried everything in its power to salvage the situation by seeking assistance from the Ministry of Agriculture. The Ministry sent a VET to assess the situation, however, it was already too late.

5. **Resource Mobilization** – the organization continues to explore alternative means of financing the activities it undertakes during the financial year, rather than depending on

the government subvention. Thus, under this thematic area, the organization was able to submit proposals for funding:

- ❖ Proposals Submitted - The organization submitted a proposal for funding to the FNB Foundation, Swaziland. The SEO proposed to buy Anti-Epileptic Drugs (AEDs) for 280 vulnerable people with epilepsy when the treatment has run out in the Public Health Institutions. This action aims to reduce the Epilepsy Treatment Gap that is characteristic of countries in Africa in general and Swaziland in particular. The people that stand to benefit most from this funding are children who's AEDs are often expensive to buy from pharmacies when there is a shortage from the government supplies.

Furthermore, the organization is planning to host the Inaugural Epilepsy Marathon in collaboration with Golden Foot Club in March 2017. The marathon is in commemoration of the International Epilepsy Day – a day celebrated all around the world aimed at raising awareness about epilepsy. The marathon is envisaged to take place in Manzini town. It is proposed that the race will begin and finish at Manzini club. Plus or minus 500 people are expected to participate in the marathon. The organization has sent out proposals to the relevant companies and stakeholders to assist in making the event a success.

- ❖ Letters of Intent/Inquiry – the IBE is committed to finding new and innovative solutions to the problems impacting people with epilepsy and their families world-wide. As part of this commitment, under its Promising Strategies Program, IBE has been providing a limited amount of financial support to the IBE chapters (which then SEO is part of) on a competitive basis for initiatives aimed at improving the quality of

life for people with epilepsy in resource challenged countries or regions. It is against this backdrop that the IBE invited IBE chapters to submit Letters of Intent to indicate their interests in submitting a proposal for consideration. The SEO was happy to submit its Letter of Intent where it was seeking \$10, 000 in funding to establish a market hub at Sikhuphe in the Lubombo region, near the KMIII International Airport. The SEO has been training a groups affected by epilepsy on the production of handcraft using indigenous and recycled materials. This hub would be used as a market place for the products.

Additionally, the SEO submitted a Letter of Inquiry (LOI) to the ROW Foundation, an organization based in the USA. The foundation is a shareholder of OWP Pharmaceuticals, a for-profit company that produces effective epilepsy medications. The SEO applied for ROW Foundation funding under the area of reducing the treatment gap and morbidity of people with epilepsy. The SEO is proposing that ROW Foundation donates AEDs to Swaziland in an attempt to bridge the treatment gap that currently exists in the country. The LOI was well received by the foundation.

- ❖ Lobbying - the organization saw an opportunity during SADC Ministers of Health meeting in Swaziland to lobby for support of epilepsy in the SADC region. The organization released a press statement through the Swazi Observer urging member states to explore the unprecedented opportunity of the approval of the WHO Resolution on the Global Burden of Epilepsy to the best of our advantage. It also pleaded with Member States of the SADC region to include epilepsy in the agenda of the next SADC meeting.

PERFORMANCE

THEMATIC AREA	ACTIVITIES INVOLVED		TOTAL No of activities	Amount
1. Advocacy & Awareness	Media Programs	Events as and when Organized		
	Newspaper Articles		3	E1,500.00
		1 Breakfast meeting		E1,185.60
	Radio Programs	Mental Health Day	2	
	Television Programs	Presentation at Ekwetsembeni Special School Mkhuzweni community visit	1	
	IEC Material	Distributed Pamphlets at events.		
	None printed			
	Abstract was submitted for a poster to be presented at the African Epilepsy Congress, Dakar Senegal			
	Digital Story Telling content submitted			
	Donation soccer kit			E3, 500.00

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Total	Total		E4,685.60
2.Impact Mitigation	Community visit IBE youth project at Luve Thulwane Dairy Farming	3	
	Tikhuba House Project *Building materials (10 Bags of Cement & Sand delivery cost) *Airtime for coordinating the project		E1,000.00 E40.00
	School Fees Paid school fees for a form 4 student at Swazi National High School	2	E3,336.27
	School Fees paid last quarter, payment withdrawn this quarter		E2,329.00
	Food Hampers Bought Rice, Chicken portions and bread for a vulnerable woman living with epilepsy at Luve	1	
	Food Allowance for Mkhuzweni Clinic		E120.00
	Bus fare for Maloma and Buhleni patient		E100.00
Total			E7,525.27
3.Resource Mobilization	Letter of intent/inquiry and Proposal Submitted Letter of Intent to the IBE requesting \$10, 000 funding Letter of Inquiry to ROW Foundation requesting a donation of AEDs Proposals submitted to different companies to source funds for Inaugural Epilepsy Marathon Lobbying for support of epilepsy in the SADC region	8	
	Golf Outstanding payment EU Proposal documentation Food Allowance for Officers that were documenting EU proposal		E17,065.00 E3,000.00 E226.80
Total			E20,291.80
4.Capacity Building	TeleEEG Training * A doctor and nurse from the UK were at the Mbabane Government Hospital for days to train the 2 local nurses operating the TeleEEG machine	1	

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			E5,000.00
	*International Relations		E7,821.00
	* Skills development and support groups		
	Food for members of Luve project		E540.15
	Raw materials for Luve project		E606.00
	Coordinating Luve Meeting		E50.00
	Nett Wire for Luve Youth Project		E89.40
	Beads for Luve Project-(Beads)		E46.00
Total	<input type="checkbox"/> <input type="checkbox"/>		E14,152.55
5.Capital Projects	Proposals submitted	2	
	*E5 million proposal was submitted to the EU to fund the construction of the Epilepsy Centre		
	*Proposal to provide timber material for the construction of a market place at Sikhuphe was submitted to Montigny		
	Sikhuphe project		E20,000.00
	Sikhuphe Fencing Delivery		E590.00
	Sikhuphe Delivery Food Allowance for 2 Officers		E240.00
	Delivery Charges		E2,000.00
	Earnings and food for 2 Direct Labors, Food for Driver		E287.70
	Sikhuphe Project, Rent @ 300, Clearing : 300, Charge 6		E606.00
	Agri- business infrastructure		
	Food Allowance for Community Development Officer		E60.00
	Bales of Hay for Thulwane project		E700.00
	Thulwane Products		E697.00
	Coordinating @ Thulwane project		E39.30
Total			E25,220.00
Admin	Personnel cost		E67,132.77
Fuel	2 Vehicles		
	Accruals Second Quarter		E11,415.18
	Petrol Cost		E21,584.02
	Prepayment		E2,000.80
Total			E35,000.00
Communication	Telephone bills, internet cost		E17,760.57

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Professional And Special Services	Auditors Insurance and Tracking		E19,000.00
Consumable Materials And Supplies	Office furniture, consumables and supplies		
	Office Equipment Repairs and Maintenance		E3,000.00
	3 Printer MLT310 Toners were bought, 1 was paid for 2 accrued		E1,060.00
	News paper, Office Perishables,		E2,693.40
Total			E6,753.40
Durable Materials And Equipment	One Geha Shredder was bought		E1,350.00
	Part Payment of Office furniture		E5,000.00
Total			E6,350.00
Meetings	Consultative and stakeholders meetings		E8,452.00
Vehicle Charges	2 vehicles repairs and maintenance cost		E8,726.98
Bank charges	2 accounts bank charges (Standard bank & Building Society)		E3,115.66
Board allowance	Sitting allowance		E10,720.00
			E256,386.60

FINANCIAL STATEMENT

STANDARD BANK ACCOUNT

CASH BOOK SUMMARY

Opening balance *as at 1st October*
2016

E30,018.99

ADD: Receipts

Swaziland
Government
Building Society
Other receipts
Bank interest
Reversal
Total receipts

E250,000.00
E11,400.00
E687.71
E0.00
E4,489.21
E266,576.92

THIRD QUARTER PARLIAMENT REPORT: 2016/17

	E296,595.91
LESS: Payments	E251,500.90
 Closing balance as at 31st December 2016	E45,095.01

**BUILDING SOCIETY
ACCOUNT
CASH BOOK SUMMARY**

Opening balance <i>as at 1st October 2016</i>	E16,332.01
ADD: Receipts	
Swaziland Government	E0.00
Other receipts	E0.00
Bank interest	E0.00
Reversal	E0.00
Total receipts	E0.00
	E16,332.01
LESS: Payments	E4,885.70
Cash Deposit to Standard Bank Account	E11,400.00
	E16,285.70
 Closing balance as at 31st December 2016	E46.31

Performance of Advocacy & Awareness Programmatic Area: This area continues to perform better than the rest of the organization’s thematic areas. The advocacy and awareness activities especially those related to the TeleEEG machine has resulted in the increase of the office traffic from the public seeking more information about the EEG as well as general inquiries about epilepsy and how the organization assist those people affected by the condition. The media has played a major role in dissemination of the information.

Performance under Resource Mobilization: This area of intervention was the 2nd best performing in the 3rd quarter. The organization has sent out proposals to seek alternative sources of funding to finance its activities. One proposal that is worth mentioning is that which was sent to the EU seeking a funding of E5 million

Performance under Impact Mitigation: Mitigating the needs and health challenges of people living with epilepsy and with other disabilities is not as easy exercise as one can imagine. However, for this quarter the organization was able to provide pay schools fees, donate schools uniforms, as well as donate food hampers to the vulnerable people with epilepsy.

Performance of Capacity Building: under this area of intervention the training of the two local nurses on the technical skills of operating the EEG machine was one remarkable achievement.

Performance for Capital Projects: Under this strategic area prioritized activities were done by the Organization which included seeking for donations towards the construction of the Epilepsy Centre at Sikhuphe.

ACHIEVEMENTS

- ❖ The Organization managed to reach 3 communities this quarter which indicates an over performance by 1 communities, since the Ministry of Health performance tool had made an approximation of at least 2 community.
- ❖ The organization managed to provide training to the 2 local nurses at the Mbabane Government Hospital. The nurses were trained on the technical expertise of applying the EEG electrodes. The nurses now have the technical confidence to operate the EEG. The training was conducted by Dr. Anne Clarke from the UK who was accompanied by her nurse. The Doctor was in the country for 7 days.

- ❖ The organization established new relations with international organizations such as ROW Foundation who are potential donors.

CHALLENGES

- ❖ Inconsistent supply of AEDs is one major problem faced by people with epilepsy in Swaziland. Consistent access to anti-epileptic drugs is cited by the International League Against Epilepsy (ILAE) as “both a cause of the treatment gap and the single most important obstacle to bridging the gap.” The epilepsy treatment gap is defined as the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as percentage.
- ❖ Inadequate skilled manpower is another major obstacle in the treatment and management of epilepsy in Swaziland. Currently, there is no neurologist in the country. Diagnosis is made by hospital physicians and general physicians as well as nurses. The deficiency of neurologists translates into sparse neurological training of primary care physicians, clinical officers, nurses, and community health workers. Furthermore, the supply of diagnostic equipment to aid in the management of epilepsy (EEG machines, CT and MRI scanners) is extremely limited. There is currently one EEG machine which is expected to cover the whole population of Swaziland.
- ❖ People with epilepsy in Swaziland are still faced with stigma and discrimination. The affliction, at times, has been described as being the result of witchcraft, not only in the past, but the present. Stigma and discrimination give people with epilepsy less of a chance of getting an education, a job or even getting married. Their families are also often shunned. But it doesn't have to be that way. The organization together with the

Ministry of Health still have a long way to go in terms of educating people about epilepsy.

- ❖ The increase in the number of cases of violence against people with epilepsy is disturbing. Local newspapers have reported on 2 teenage girls have been raped by a nurse and a boyfriend, respectively, in their state of vulnerability. Or how some are being beaten by family members when they suffer seizures. The organization condemn such acts and we are grateful that the long arm of the law has dealt with those cases accordingly.

RECOMMENDATIONS

- ❖ The organization needs to engage more in activities that will sensitize communities in order to recognize that people who have epilepsy often don't know that they have epilepsy - and if they do know that they have epilepsy, don't know that it can actually be controlled by medical treatment. This will thus reduce and the stigma associated with the condition.
- ❖ Increasing the supply of health workers capable of diagnosing and treating epilepsy is a critical need. The small numbers of, or lack of, physicians trained in neurology in Swaziland represents an obvious deficiency that can only be remedied by additional post-graduate training programs, and partnership with neurology training programs in developed countries. The majority of people with epilepsy in sub-Saharan Africa will need to be treated by primary healthcare providers at the community level.

- ❖ Reliable procurement and distribution of anti-epileptic medications are critical. The Ministry of Health needs to do better in this regard. We cannot continue to have drugs shortage for a prolonged period of time.
- ❖ Moreover, an introduction of a further antiepileptic drug is an option that needs to be explored by the government. Currently sodium valproate, carbamazepine and phenobarbitone are antiepileptic drugs available free of charge in Swaziland. Sodium valproate is the drug of choice in generalised tonic clonic seizures. However, sodium valproate is known to cause birth defects. While carbamazepine or phenobarbitone might be able to substitute for sodium valproate in women of child bearing age these drugs can worsen types of epilepsy known as myoclonic seizures and absences. Another choice of antiepileptic medication would be useful in this case.
- ❖ We also recommend that the Ministry officials attend the different Epilepsy Congress organized jointly by the ILAE and the International Bureau for Epilepsy scheduled throughout the year. The 3rd African Epilepsy Congress will take place in Dakar from May 5 to 17, 2017. Building on the success of the first two AECs, in Cape Town in 2014 and Nairobi in 2012, the scientific programme of the congress promises to provide information on new developments in the field of epilepsy, to share knowledge and to impart an insight into the diagnosis and treatment of epilepsy at grassroots level in Africa, and shows the firm commitment to improve the quality of life of people with epilepsy through support of education, research, knowledge dissemination and patient care.
- ❖ The United Nations needs to include epilepsy on its list of non-communicable diseases that demand more attention. Also the Government of Swaziland needs recognize epilepsy

as a major non-communicable disease. Epilepsy is frequently viewed, incorrectly, as a non-fatal and non-disabling condition. People with epilepsy have a mortality rate 2–3 times higher than the general population (WHO, 2016). Causes of death include status epilepticus (prolonged uncontrolled convulsions), sudden unexplained death in epilepsy (SUDEP), and suicide. Educational achievement, employment rates, and quality of life are all substantially lower for people with epilepsy.

- ❖ Lastly, more epidemiologic research is needed to document the social and economic impact of epilepsy in Swaziland for policy makers and funding agencies.

CONCLUSION

The future of epilepsy treatment in Swaziland will remain challenging given the many barriers discussed above. In the short term, improving the availability of phenobarbital and other generic first-line antiepileptic drugs should be given the highest priority. The more difficult challenge will be to increase the number of skilled healthcare workers capable of diagnosing and treating epilepsy. However, as an organization we will continue to vigorously pursue our vision of developing and promoting areas of intervention for the effective treatment and social integration of people afflicted and affected by epilepsy in Swaziland.