

FOURTH QUARTER PARLIAMENT
REPORT 2016/2017



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BACKGROUND INFORMATION

Epilepsy affects 50 million people worldwide, and 80% of them live in the developing world. An individual with epilepsy suffers recurrent seizures unprovoked by acute brain insults or metabolic derangements. Seizures are characterized by a brief period of uncontrolled involuntary shaking. They may be partial, involving only one part of the body, or generalized, involving the entire body, and they may be accompanied by loss of consciousness and of control of bowel or bladder function. Some individuals continue to have frequent seizures despite optimal treatment with anti-epileptic drugs. However, more than 70% of patients who are treated achieve long-term remission or freedom from seizures, usually within 5 years of diagnosis.

Cost-effective epilepsy treatments are available and an accurate diagnosis can be made without technological equipment. Nonetheless, a vast majority of individuals with epilepsy in many resource-poor regions do not receive treatment. Untreated epilepsy is a critical public health issue, as people with untreated epilepsy face potentially devastating social consequences and poor health outcomes. Due to stigma, many persons with epilepsy have lower employment and education levels and lower socioeconomic status. For example, children with epilepsy who have a seizure at school may be dismissed, while adults may be barred from marriage or employment. In addition, persons with epilepsy have poor health outcomes, including greater psychological distress, more physical injuries such as fractures and burns, and increased mortality.

The epilepsy treatment gap, defined as the proportion of people with epilepsy who require treatment but do not receive it, has been proposed as a useful parameter to compare access to and quality of care for epilepsy patients across populations. Prior anecdotal and descriptive estimates suggest a treatment gap of more than 80% in many low-income countries.

Historically, epilepsy has received little public health attention despite poor health outcomes and potentially devastating social consequences from untreated disease. In recent years, many countries have undertaken initiatives to decrease the epilepsy treatment gap, notably the demonstration projects such as the Global Campaign Against Epilepsy, conducted jointly by the International League against Epilepsy, the International Bureau for Epilepsy and the World Health Organization.

PREVELENCE OF EPILEPSY

WHO estimates that there are over 65 million people currently living with epilepsy worldwide. Out of the 65 million, 45 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.

EPILEPSY IN SWAZILAND

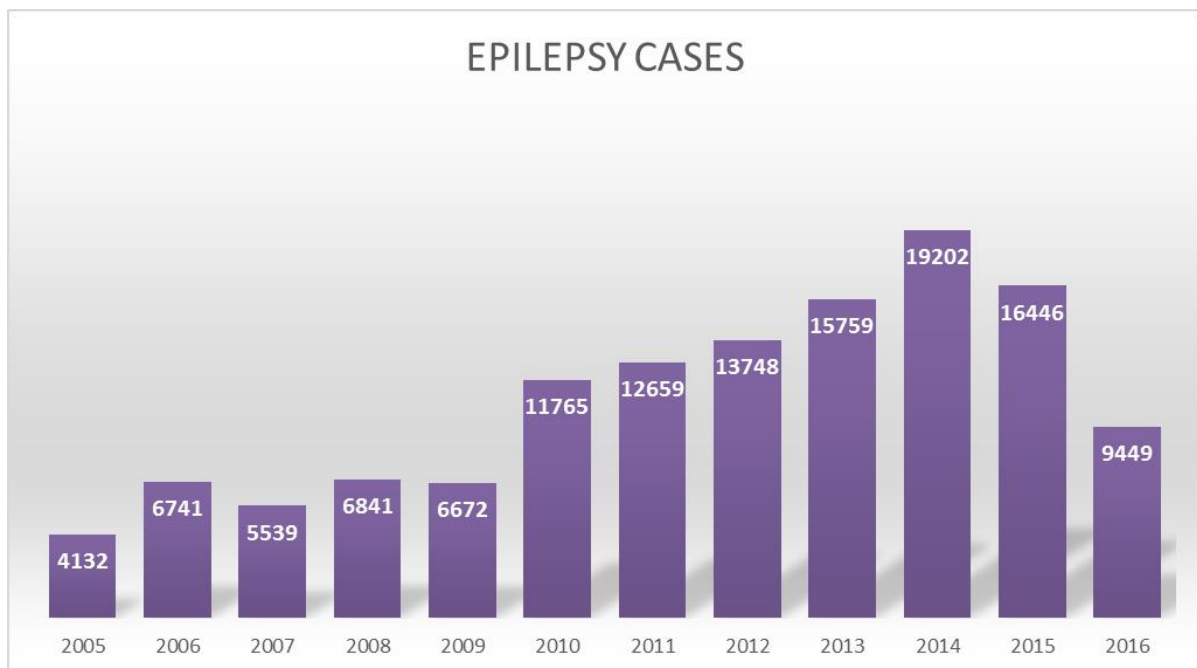
The Swaziland Epilepsy Organization (SEO) and the Ministry of Health are making enormous efforts in promoting the recognition of Epilepsy, its diagnosis and management. However, there are underlying issues: There is no permanent neurologist in Swaziland to help diagnose epilepsy. Diagnosis is made by 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.

AN OVERVIEW OF THE SWAZILAND EPILEPSY ORGANISATION (SEO)

Swaziland Epilepsy Organisation is under the patronage of HRH Prince Bandzile. It is a Non-Profit making 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 organisation strengthens advocacy issues surrounding

epilepsy and initiates capacity building, skills and the sharing of information through dissemination to all citizens.

Its goals include but not limited to the following:

- ❖ Providing a platform for general epilepsy awareness
- ❖ 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

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”.

Mission statement - “To improve the accessibility of treatment, services and prevention of epilepsy in the Kingdom of Swaziland”.

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.

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:

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 programme.
2. **Impact mitigation** which focuses on health provision and livelihood sustenance.

3. **Resource mobilization** 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.

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

5. **Capital projects** which involves the organization’s major goal, the construction of an epilepsy clinic centre.

PROGRAMAMATIC PERFORMANCE

Table 1

PROGRAMME	OFFICE VISITS	TELEPHONE CALLS	Grand Total
Count of TOTAL	97	115	212

Figure 2

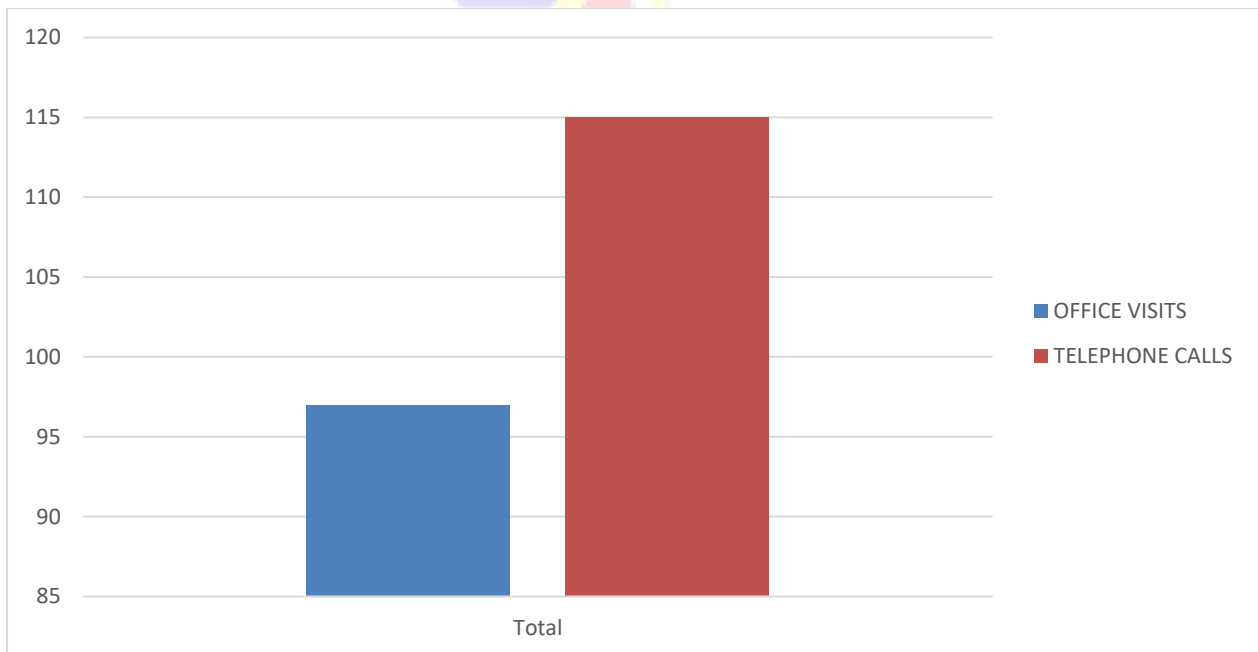


Figure 2 and the table 1 above have been extracted from the organization’s checklist and database reporting tool. It shows that in the 4th quarter (January – March), the organization’s telephone calls were 115 and 97 office visits (Clients Volume) from the public enquiring about

the services the organization provides or seeking assistance with economic and health issues related to epilepsy.

The increase in both the telephone calls and office visits from the last quarters may be attributed to the establishment of the TeleEEG machine which was set up at the Mbabane Government Hospital – Psychiatric Unit. Furthermore, the organization had adverts which were aired in SBIS 1 and 2 which were informing the public about the existence of the organization as well as advertising the Epilepsy Marathon. Hence, people would hear the radio commercials and they would call or visit our offices to enquire more about our services.

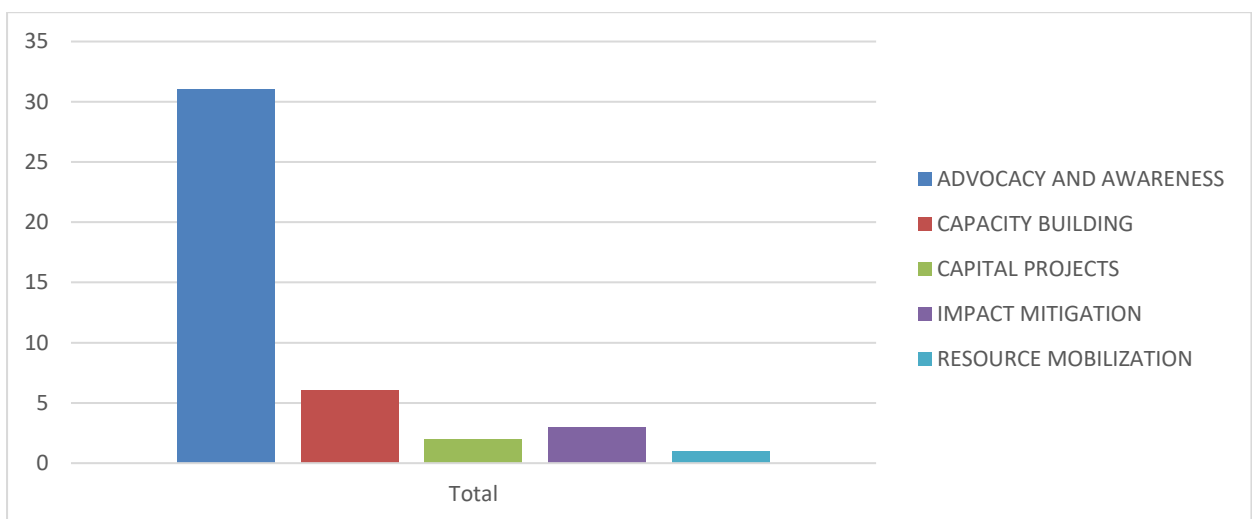
HIGHLIGHTS

Figure 2

THEMATIC AREA	ADVOCACY AND AWARENESS	CAPACITY BUILDING	CAPITAL PROJECTS	IMPACT MITIGATION	RESOURCE MOBILIZATION	Grand Total
Count of ACTIVITY	31	6	2	3	1	43

The table show the thematic areas of the organization with the count of activity in each thematic area. Advocacy and Awareness being our core focus area has the highest number of activity.

Figure 3



The figure above has been derived from the organization’s Checklist and Database.

ADVOCACY AND AWARENESS – The organization undertook 31 advocacy and awareness activities this quarter, the highest it has been this financial year. These activities are as follows:

1. **Media Programmes** – the organization continues to use the various media houses in the country to disseminate information on activities that the organization undertakes. This quarter we did 4 radio commercials of which 3 of them were aired on national radio (SBIS 1 and 2). Two of these commercials were about the Epilepsy Race which the organization successfully hosted on Sunday, 2 April 2017. The third commercial was on the International Epilepsy Day with the theme “Putting Epilepsy in the picture” which was inviting the public to participate during the celebration by taking a selfie or group photo and then post it on social media networks with the #EpilepsyDay. The main purpose for this was to make #EpilepsyDay trend in Swaziland. Furthermore, the public was informed about the day through SBIS 1 and 2 news.

2. **Media Breakfast Meeting** – the organization organized a breakfast meeting for the media wherein we presented a Swazi that won a global award for epilepsy portrait. The young man Lungelo Dube responded to a call by the organization where we invited all Swazi's to participate in an international art competition organized by the International Bureau for Epilepsy (IBE) with the theme ‘Putting Epilepsy in the Picture’. The art competition was dubbed “Artistic Waves’ was in celebration of the International Epilepsy Day.

Present during the breakfast meeting was the Minister of Sports, Culture and Youth Affairs David ‘Cruiser’ Ngcamphalala who was especially impressed with the young man's work. He tasked the Swaziland National Council of Arts and Culture to nurture the talent and make sure he gets all the necessary support. Moreover, the Minister thanked the SEO for its work in the country and further encouraged the organization to continue supporting and taking care of the people with epilepsy in Swaziland.

3. **Epilepsy Race Launch** – the organization launched the maiden Epilepsy 10 KM and 5 KM Run at Rudi's Kitchen in Matsapha. Present during the launch were representatives from the event sponsors (Embassy of the Republic of China on Taiwan, Macmillan, Puma Energy, Swaziland Beverages) and the media houses. The organization collected E33 800 in cash to prepare for the race scheduled for Manzini Club on April 2, 2017 with other endorsements coming in the form of services.

The event already adds to the jam packed Athletics Association of Swaziland (AAS) calendar. The event is the organization's way of creating awareness for the epilepsy condition, hence the event has the theme: 'Putting Epilepsy in the Picture'.

4. Presentations – as part of our programme to educate the nation on epilepsy, the organization honored an invite by the Prime Minister's Office to promote epilepsy awareness amongst its staff. The prime minister's office offer a wellness program in an effort to promote employee health and productivity and reduce health related costs.

Speaking at the meeting, the National Director pointed out that having epilepsy does not necessarily stop someone from doing the job they want, but it simply means there are some conditions which can affect them at work. Whether someone's epilepsy affects their work depends on whether they have seizures, what their seizure are like, and how often they happen. It also depends on the type of work they do, and nay risks that having seizures at work might bring.

The Swaziland Occupational Health Act, 2001 states that employers are responsible for making sure that all their employees are safe at work and are protected from possible dangers to their health. In this regard, therefore, employees are encouraged to disclose their epilepsy to the employer. In turn, employers are expected to make reasonable adjustments to the work or environment for an employee with epilepsy.

The staff members were made aware that employers cannot legally refuse to give people with epilepsy a job just because of their condition. However, what they need to consider their epilepsy and what the job involves, to ensure their safety and that of other employees.

The organization was also invited by the Central Statistics Office (CSO) to come and educate Census Supervisors about epilepsy since question concerning the condition have been included in this year's National Population and Housing Census. The supervisors were educated on how to pose the questions using the right terms so that they don't offend or confuse the respondent which may lead to under reporting or over reporting of the number of people with epilepsy in Swaziland.

The main reasons why epilepsy is included in National Population and Housing Census is to get the total number of people with epilepsy and also determine the "Epilepsy Treatment

Gap” which is defined as as the number of people with active epilepsy not on treatment (diagnostic and therapeutic) or on inadequate treatment, expressed as a percentage of the total number with active epilepsy.

5. International Epilepsy Day/Epi-Yellow Valentine’s Day – the organization was at the Prime Minister's premises to advocate and raise epilepsy awareness amongst Cabinet Ministers and staff. This was during the celebration of the Epi-Yellow Valentine’s Day on the 14th of February 2017. Given their tight Tuesday schedule, members of the Cabinet were able to spare a few minutes to celebrate an ‘Epi-Yellow Valentine’s Day.’

In previous years, the organization hosted celebrated the day at the various Tinkhundla centres. However, this year we decided to go back to the Executive arm of Government so that we remind them of the condition and they could, in turn, relay the message back to their ministries.

Upon arrival, a majority of ministers, including the Prime Minister Sibusiso Barnabas Dlamini, wore a wreath of yellow flowers around their necks as they briefly celebrated Valentine’s Day before heading straight into their meeting.

This was a high level activity meant to improve visibility of needs of people with epilepsy. Commenting on the work being done in Swaziland, Mr Zimba, current President for Africa and IBE Treasurer – elect, said “If all of us were working like Mbuso, Epilepsy stigma would have been eradicated. Good work Mbuso” while Godfreda Bupanda said “Mbuso you are a selfless visionary. You make Swaziland proud. Keep up the good work.”

6. Awareness Campaign – the organization participated in a World TB Day Build Up Campaign which was held at the Mbabane Bus Rank. Annually on the 24th March the country joins the rest of the world in commemorating World TB day. This day provides an opportunity to raise awareness, showcase support, problems and solutions gained n TB control efforts. While great strides have been made to control and cure TB, people still get sick and die from the disease in the country. There is still a lot that needs to be done by the country to eliminate the disease.

The theme for this year is “UNITE TO END TB”. This theme highlights that TB is still a life threatening problem, despite the declining number of cases. It encourages us a country to go

out to the workplace and communities to find the missing cases. SEO's participation in the build-up campaign was to drive the message that TB is not the health concern that the country should focus on. There are other disease and/or conditions such as epilepsy that also affects a large number of the Swazi population.

On the day we were able to reach at least 100 people at the Bus Rank whom we educated about epilepsy and handed out pamphlets on Epilepsy and Pregnancy.

7. **IEC Material** – the organization distributed 200 pamphlets about "Epilepsy and Pregnancy" at Luve Community. The material was placed in the different shops at the small town. A further 200 pamphlets on the same subject were placed at the National Psychiatric Referral Hospital.

Additionally, the organization printed a pull up banner for International Epilepsy Day with the theme "Putting epilepsy in the picture" with the painting that won 1st Prize for the International Art Competition by the IBE.

8. **Donation** – in its endeavour to promote epilepsy awareness among the general public, the organization donated a football kit worth E7, 500 to Luve Cosmos - football team playing in the Manzini Super League. The aim of the donation is to raise epilepsy awareness in sport. The organization wishes to be more involved in sport because sport especially football has the potential to draw a large number of people together. Through branding and donations made to the various sporting codes the organization can be able to disseminate information about epilepsy. Luve Cosmos fully supports the fight against Epilepsy.

CAPACITY BUILDING – the organization undertook five (5) capacity building activities in the 4th quarter. These are as follows:

1. **National Population and Housing Census** – upon hearing that the country will be undertaking a census count where the King mentioned that everyone and every household in the country will be visited and certain information will be required from each and every individual – the organization approached the Central Statistics Office (CSO) to find out if they can also include questions about epilepsy in the census.

The CSO expressed its willingness to assist and that they can include two questions on epilepsy but only after we have done a bit of research from our colleagues on how we they can

structure the questions. It was only clearly explained to us that to really dig deeper on epilepsy, probably a survey would be a better option as census only asks the basic questions.

The organization was able to come up with the questions that would help us know the prevalence of epilepsy in Swaziland and those with active epilepsy who is receiving anti-epileptic drugs. This would give a guide on the “treatment gap.”

True to their word, the CSO team approved the question and were consequently included in the upcoming National Population and Housing Census.

2. Elections and Boundaries Commission Workshop – the organization participated in one day workshop that was held at the Tums George hotel hosted by the Elections and Boundaries Commission (EBC) together with the FODSWA consultative and its members. The main purpose of the workshop was to discuss ways in which people living with disabilities can participate in the 2018 upcoming elections.

The floor was open to discussions on how/what the EBC can do to improve ways of voting for people with disabilities and the FODSWA and its members shared their ideas. The panel requested that there be new laws regarding the rights of people with disabilities to vote and be voted for; that people with disabilities should occupy permanent seats in both Houses of Parliament (House of Assembly and the House of Senate); that voting papers should be written in braille to cater for the visually impaired.

3. CANGO NGO Open Day – the organization participated in the open day for NGO’s organized by the Coordinating Assembly of NGOs (CANGO) on the 24th March 2017 at UNISWA Sports Emporium. CANGO is the coordinating body of Non-Governmental Organizations in Swaziland and was established in 1983 originally as a network of Primary Health Care for NGOs. CANGO’s long term vision is “Improved Quality of life for the Swazi Population” and CANGO’s mission is to “Coordinate, advocate, strengthen capacity and empower NGOs to effectively deliver on their mandates” In a bid to fulfil her mandate, CANGO annually hosts the NGO Open Day which has become a trademark for NGOs to market their products and services to the broader public. The 2017 theme is, “Invest in health, build a safer future.”

Activities on the day included:

- Keynote address from SWABCHA Director – she highlighted the importance of having workplace wellness programmes. She encouraged organizations present to start wellness programmes to reduce health related costs organization may incur in the event an employee falls sick or dies due chronic illnesses which may have been prevented. Furthermore, she stated that there are two components of a wellness program: 1) Lifestyle Management – how well are we as an organization; 2) Disease Management – create an environment that will support employees on medication.
- Aerobics/Mental Wellness/Stress Management exercise for NGO personnel led by Aerobics Instructors & PSHACC.
- Different games
- Displays show casting the work of different NGOs in the following clusters: SRH, HIV/AIDS, Counselling, Gender, Food Security and Livelihood, Environment, Children’s Issues and other emerging issues such as Climate Change.

4. Hhukwini Mushroom Workshop – following the Ministry of Agriculture’s approval of our request to utilize the agriculture shed premises to construct a mushroom cropping house for the Epilepsy Support Group – the Mushroom Development Unit (MDU) conducted a 3 day workshop for epilepsy support group members at Hhukwini Inkhundla. The overall objectives of the workshop was to build the capacity of the epilepsy support group members on mushroom production in order to equip them with the necessary skills and principles of producing healthy mushrooms.

The objective was achieved through lectures, practical demonstrations and discussions. In addition, the MDU provided mushroom seeds, planting grass, sterilizing liquids and planting bags.

This is an on-going project which falls under one of the organizations thematic area known as Capital Projects. The organization over the past years has successfully launched income generative projects for people with epilepsy in Thulwane/Timbutini (Handcraft, Dairy Farming, Vegetable Gardening), and Luvu (Youth Empowerment Initiative).

At the end of the workshop, 28 participants were awarded with certificates of attendance. Present during the award ceremony was the Hhukwini MP Mr. Saladin Magagula, the National Director of the SEO Mr. Mbusomuni Mahlalela. The MP encouraged full participation and

commitment from the support group members for the project to become a success. The National Director was also pleased with the successful completion of the workshop. The members now have the relevant skills which they will apply in order to improve their lives.

The workshop played a major role in sensitizing the community about epilepsy and promoting full participation of all stakeholders.

CAPITAL PROJECTS – the organization undertook only two (2) activities which fall under this thematic areas:

1. **Sikhuphe Trading Hub** – the organization engaged a consultant to design and lay out the proposed structure for the proposed trading facility at Sikhuphe. The cost estimate for the proposed structure is E112, 763. 03.

Consequently, the organization submitted a proposal to Old Mutual Life Assurance Company were are requesting financial assistance with the establishment of the trading facility for epilepsy support group members engaging in handcraft and other income generating projects. These support groups are a forum to address matters affecting people with epilepsy and related disabilities. They are a psycho-social support system. These groups also comprise of abled bodied people to break down stigma and discrimination.

Members of the support groups are trained on life skills, handcraft entrepreneurship and many other income generating activities as identified by the assessment to complement their economic status. It is against this backdrop that the SEO seeks to build a trading facility at Sikhuphe which is a tourist zone and closer to the King Mswati III International Airport which is an ideal location for selling handcraft to immigrants, tourists and locals. This structure will comprise of an open gallery for displaying the handcraft products as well office space. Already we have two (2) support groups with handcraft products ready for market. The organization is already engaging market facilities in and outside the country's border's (i.e., Botswana) to sell these products.

IMPACT MITIGATION – there were only three (3) activities undertaken under this focal area which involves provision of health and livelihood sustenance. The activities are as follows:

1. **School fees paid** – E1, 000 school fees was paid to a Form 4 male student with epilepsy from Swazi National High School.

2. **Food Hampers** – the organization donated 5 bags of Rice (10 kg) to a family of a 60 year old epileptic woman killed by a tall tree measuring 10 metres, which fell on her. The woman was on her way to the launch of the epilepsy support group at Hhukwini Inkhundla when the incident happened. The bags of rice was a contribution towards the funeral of the member of the support group.

3. **Dairy Farming** – even in the 4th quarter, the organization continued to support the dairy farming project at Thulwane.

RESOURCE MOBILIZATION – only one (1) activity was under taken under this thematic area:

1. **Epilepsy Race** – the organization submitted proposals to companies requesting for sponsorship towards the Epilepsy Race event aimed at promoting epilepsy awareness as well as raising funds for the organization to effectively carry out its mandate of taking care of needs of people with epilepsy in the country.

FINANCIAL PERFORMANCE OF THEMATIC AREAS

THEMATIC AREA	ACTIVITIES INVOLVED	TOTAL NO. OF ACTIVITIES	AMOUNT (SZL)
ADVOCACY AND AWARENESS	Radio Programmes	36	E3 000,00
	Radio Commercials Voice Edition	4	E10 775,00
	TV Programmes	10	
	Newspaper Articles	4	E1 524,00
	Football Kit Donation	1	E6 226,94
	Pamphlets Distributed	600	

	EEG African Epilepsy Congress Poster	1	E1 900,00
	Cravats and Head Wraps	10	E1 920,00
	Epilepsy Day Pull-up Banner	1	E3 453,00
	Art Competition Breakf. Meeting	1	E2 000,00
	Epilepsy Race Launch	1	E1 512,00
	Lobbying - Epilepsy Day Celebration	1	E169,00
	Wafa Wafa Marathon	1	
	Awareness Campaign	1	
	Epilepsy Marathon	1	E22 226,96
TOTAL			E54 706,90
CAPACITY BUILDING	Population Census Meeting	2	
	FA Football Symposium	1	
	EBC Workshop	1	
	Mushroom Workshop	3	
	NGO's Team Building	1	
	Dullstroom Golf Day	1	E4 957,56

	International Relations	3	E23 467,50
TOTAL			E28 425,06
CAPITAL PROJECTS	Sikhuphe Proposals Submitted	1	
	Sikhuphe Design and Layout	1	E1 500,00
	IBE Luvu Handcraft Project	1	E346,00
	Dairy Farming	1	E1 310,00
TOTAL			E11 461,00
IMPACT MITIGATION	School fees	1	E1 000,00
	Food Hampers	1	E384,95
	Contingency		E4 106,00
	Frail care	2	E108,40
	Sicelwini Project	1	E606,00
TOTAL			E6 205,35
RESOURCE MOBILIZATION	Epilepsy Race Proposals Submitted	29	
ADMINISTRATION	Personnel Cost		E79 489,30
FUEL (2 Vehicles)	Prepayment b/d		E2 000,80
	Petrol Cost		-E25 661,92
	Prepayment		-E11 338,88
TOTAL			E35 000,00

COMMUNICATION	Telephone Bills, Airtime, Internet Cost	E25 206,00
PROFESSIONAL & SPECIAL SERVICES	Insurance and Tracking Cost	E2 940,00
CONSUMABLE MATERIALS & SUPPLIES	Office furniture, consumables & supplies	
	Newspaper, Office Perishables, Tissue Rolls and Stationery	E3 575,00
	Office Equipment Repairs and Maintenance	E1 500,00
	Toner for Printer SCX-4521 & Typek	E2 110,00
TOTAL		E7 185,00
MEETINGS	Consultative and stakeholders meetings	E8 610,00
VEHICLES CHARGES	2 vehicles repairs & maintenance cost	E6 577,49
BANK CHARGES	2 accounts (Standard Bank & Building Society)	E3 683,07
REVERSAL		E2 700,00
TOTAL		E272 189,17

Performance of Advocacy and Awareness – the organization undertook 31 activities in total under this thematic. Some of these activities are outlined in the table above. Advocacy and Awareness is the core of what we do as organization that ensure public education about

epilepsy as well as protecting the rights of people living with the condition in the country. Thus, this thematic area is the highest performing in terms of activities carried out. Its total expenditure also reflects same as more money was spent on this area as compared to the other thematic areas. It is 20% of the total expenditure. The total expenditure increased by 91% from last quarter's E4 685,60. This increase is attributed to the introduction of the Epilepsy Race as a vehicle to promote epilepsy awareness.

Performance of Capacity Building – total expenditure for this thematic area increased by 50% compared from the last quarter, 82% of the expenditure was on international relations – where the organization would engage with international organizations in areas of mutual interest.

Performance of Impact Mitigation – compared to the last quarter, the expenditure for this thematic area decreased by 17.5%. In this area the organization carry out activities that will minimize the effects that the condition has on the lives of people suffering from it and their family members.

Performance of Resource Mobilization – in this quarter the organization did not carry out an activity that will require financing under this thematic area. Hence, the total expenditure for it was E0,00. This is a financial improvement from the last quarter where the organization spent over E20, 000 on resource mobilization activities.

Performance of Capital Projects – compared from the last quarter this thematic area showed great improvement. Total expenditure decreased by 54.6%. As it was highlighted in the 3rd quarter report, the country was under a drought spell for the past years which affected the organizations capital projects such as the vegetable gardening and dairy farming. Produce from these two projects slumped due to the drought which resulted to a cash flow problems.

However, the situation this years improved hence the decrease in cash flow injection towards the running of the capital projects.

Performance of Administration - the financial performance of the administration of the organization remain relatively the same in all quarters. One anomaly that could be noted in the increase in communication costs. This is due to varying reasons mainly, the use of the internet to upload EGG files which has since been stopped.

STANDARD BANK ACCOUNT

CASH BOOK SUMMARY

Opening balance as at 1st January 2017

E45,095.01

ADD: Receipts

Swaziland Government Building Society	E250,000.00
Other receipts	E0.00
Bank interest	E29,485.23
Reversal	E0.00
	E2,700.00
Total receipts	E282,185.23

E327,280.24

LESS: Payments

E272,189.17

Closing balance as at 31st March 2017

E55,091.07

BUILDING SOCIETY ACCOUNT

CASH BOOK SUMMARY

Opening balance as at 1st January 2017

E46.31

ADD: Receipts

Swaziland Government	E0.00
Other receipts	E0.00
Bank interest	E0.00
Reversal	E0.00
Total receipts	E0.00

E46.31

LESS: Payments

E46.31

Closing balance as at 31st March 2017

E0.00

ACHIEVEMENTS

- ❖ For the first ever epilepsy has been included in the National Population and Housing Census of 2017, where questions about epilepsy will be asked to respondents to get the prevalence of the condition in the country as well as determine the treatment of gap. This data will serve as a baseline for the epilepsy national survey which the organization wishes to undertake sometime next year. A survey will enable us to dig deeper into epilepsy because a census only asks the basic question. With a census we can even get the experiences of people with epilepsy and their carers.
- ❖ Recognition from the International Bureau for Epilepsy (IBE) for our efforts in celebrating the International Epilepsy Day under the theme, “Putting Epilepsy in the Picture”. In their report, the IBE said that Swaziland Epilepsy Organisation (SEO) representatives met cabinet members who included the Prime Minister and Minister of Health (see photograph). This was a high level activity meant to improve visibility of needs of people with epilepsy. Commenting on the work being done in Swaziland, Mr Zimba, current President for Africa and IBE Treasurer – elect, said “If all of us were working like Mbuso, Epilepsy stigma would have been eradicated. Good work Mbuso” while Godfreda Bupanda said “Mbuso you are a selfless visionary. You make Swaziland proud. Keep up the good work.”

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.

