EPILEPSYAFRICA NEWS

Issue 4 **December 2017**

A newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)

Images (bottom): Epilepsy South Africa (ESA) celebrates 50 years of service to the community and some of the programs run by Epilepsy South Africa. *See report inside.*

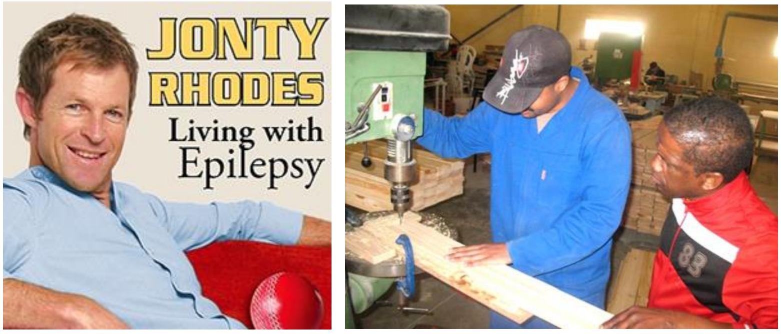


Image (right): The new logo of Kenya Association for the Welfare of People with Epilepsy (KAWE). *See report inside.*

Happy holidays

The holiday season is here. Our best wishes for Christmas day, Boxing Day, School holiday, Work holiday and the New year holiday.

Join us today

WhatsApp group for people with epilepsy and significant others: +260977789042, group for professionals interested in epilepsy: +260977789042. Epilepsy Africa **Facebook** group: https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts **Twitter**: @EpilepsyAfrica. **Email list**: We have three email lists – for social issues, for professionals and for associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrica@gmail.com.

Contents of this Newsletter

- Chapters spotlight Kenya and South Africa
- Interview with Lungelo Dube, Swaziland
- Photos (please also tell or show us what is happening where you are).
- Onchocerciasis meeting report by Anthony Zimba, IBE Treasurer.
- Opportunities and resources for associations.

About this newsletter

Editorial team: Jacob Mugumbate; Youssouf Noormamode; and Betty Barbara Nsachilwa. **Frequency**: Monthly **Distribution**: Email, IBE website and other social media. **Email contributions to**: ibeafrica@gmail.com. Enjoy your reading.

Chapter spotlight number 2, Kenya

Photo: Dr Osman Miyanji (Chairman, KAWE Board of Directors)

KAWE got international recognition for the MKifafa mobile phone platform for epilepsy awareness developed in 2013 with the support of Safaricom and Kenya Community Development Foundation. MKifafa was awarded second prize at the 2016 Epilepsy Foundation Pipeline Conference - Shark Tank Competition in San Francisco, USA. Ours was one of the 6 innovations selected, out of 65 entries from 13 countries, to be presented at the conference and was one of the two that won a prize. The prize money will go a long way to make epilepsy information widely available in Kenya. Safaricom has availed this avenue of reaching people with health information through mobile phones to organisations offering services for other Non-Communicable Diseases and the new service dubbed Fafanuka will have information on Epilepsy, Diabetes, Cancer and Heart & Blood Vessel diseases.

KAWE utilises various approaches to create epilepsy awareness and this year with support from the LOTTO Foundation, we conducted the Komesha Kifafa Epilepsy Caravan which was a series of Roadshows that made stops at 80 market centres in 14 counties in various regions of Kenya: Mombasa, Kwale & Kilifi at the Coast; Isiolo, Meru, Makueni & Machakos in Eastern; Kirinyaga & Nyeri in Central; Laikipia, Uasin Gishu & Trans Nzoia in Rift Valley; Bungoma in Western and Nairobi. Thousands were reached with epilepsy information directly and also through the media coverage of the caravan.

To increase access to epilepsy management services in remote areas of the country, KAWE partnered with the Kenya Red Cross and International Rescue Committee in improving epilepsy services in the Dadaab Refugee Camps where two KAWE clinicians provided consultancy services reviewing patients and recommending treatment plans and training the health workers on the national epilepsy management guidelines.

KAWE was also glad to host various partners at our new home during an event to officially open the new KAWE office located in Westlands at The Mirage along Chiromo Road, Unit 13, Mezzanine 1. During the occasion on 29th July 2016, we launched our new logo and the KAWE 2016 - 2020 Strategic Plan.

The implementation of the Strategic plan had a good start with achievements in each of our 4 focus areas: Health Care, Knowledge Management, Influencing & Partnerships and Institutional Development as briefly outlined in this report.

KAWE PROGRAMS

A. HEALTH CARE

In 2016 KAWE partnered with county health services in opening epilepsy clinics in 5 different counties – Taita Taveta, Mombasa, Laikipia, Kisumu and Isiolo. These new clinics registered a total of 86 new patients before end of year. KAWE provides support to these and the previously established 26 affiliate clinics in 21 counties through support visits to assist the clinicians with any challenges they face in patient management, record keeping and access to quality affordable anti-epilepsy medicines.

KAWE continues to support the Nairobi City County Health Services to run epilepsy clinics in three county public health centres: Mathare Huruma Lions, Karen and Riruta health centres where 2,160, 1,930 and 1,883 patient consultations were conducted respectively. Two Clinicians from KAWE provided services at Dadaab Refugee Camp in Garissa County as requested by the International Rescue Committee and the Kenya Red Cross. Two epilepsy missions were made to Daadab which hosts about 300,000 refugees in five camps. Given the available statistics in Kenya of two in every hundred people living with epilepsy and the incidence being higher in the rural than in urban areas, it follows that this would be a high incidence area also due to the deprived living conditions and poor health seeking behaviour of the communities hosted. There were many cases of epilepsy attributed to birth complications resulting from poor Maternal Health especially for those born at home with no assistance from a skilled health worker to attend to birth complications.

Besides conducting the patient reviews, KAWE clinicians also gave recommendations which included establishing a steady supply of medicines to avoid disruption of therapy. They noted that a lack of continuous supply of some anti-epilepsy drugs as well as constant change from one brand of same drug to another was affecting seizure control. They therefore recommended that adherence to the specific brand a patient is started on may have significant contribution to decreasing the frequency of seizures. Prompt treatment of childhood illnesses and other febrile illnesses in children may significantly lower the risk of epilepsy. This would call for community awareness campaigns to ensure a change in the health seeking behaviour at the community level.

B. KNOWLEDGE MANAGEMENT

To increase epilepsy awareness and reduce stigma, KAWE with support from LOTTO Foundation, conducted the Komesha Kifafa Epilepsy awareness caravan which was a series of road shows that made stops in 80 market centres in 14 counties across the country - Kwale, Kilifi and Mombasa at the Coast; Makueni, Machakos, Meru and Isiolo in Eastern; Nyeri and Kirinyaga in Central; Bungoma Western; Laikipia, Uasin Gishu and Trans Nzoia in Rift Valley and Nairobi. A branded truck with loud speakers would make stops at the market centres with entertainers on board to draw people’s attention and public health officers would pass on epilepsy messages. About 20,000 people were reached directly with information materials which included 1,500 t-shirts, 14,000 fliers and 2,000 posters and thousands more were reached through national media such as Citizen Radio, Nation newspaper and Nation online that mentioned it as a news item. Regional media stations in Meru, Makueni, Baliti FM in Isiolo and Nyota FM in Bungoma gave live coverage and hosted talk shows with a KAWE member of staff giving information and answering questions. KAWE also organised two epilepsy seminars for 94 primary school head teachers and teachers in Nairobi with the aim of improving seizure management for school going children and early referral for care. The Community Health Workers (CHWs) who volunteer at the epilepsy clinics also reached 22,790 people through epilepsy awareness sessions in churches, schools and other public meetings. KAWE part time website and social media content manager - Cecilia Gathoni conducting an epilepsy awareness session at a Chief’s baraza

In December 2016, the new look KAWE website was launched. This is to keep up with increased use of the internet as an information source especially on mobile devices. KAWE recognized the need to change from the static design of the previous website that was not as interactive. The website was modified to make the information easily accessible and pages easily navigable. Content was improved to make it easier for anybody looking for epilepsy information to quickly find it and constantly updated to address information needs based on frequently asked questions and identified knowledge gaps. This will keep our visitors well informed.

C. INFLUENCING AND PARTNERSHIPS

Dr Osman Miyanji represented KAWE in the committee established to revise the Kenya National Guidelines for the Management of Epilepsy. The Ministry of Health Non Communicable Diseases Control Division produced this second edition of the guidelines in 2016 and called on partners to support in the printing and dissemination to the health sector at county level. KAWE with support from our partners printed 300 copies and disseminated them in 13 counties to the Directors of Health. In 6 of these counties; Kwale, Taita Taveta, Laikipia, Isiolo, Makueni and Garissa, KAWE provided Continuous Medical Education to 260 health workers from county public health facilities and some private facilities to update them on the guidelines for epilepsy management.

D. INSTITUTIONAL DEVELOPMENT

To strengthen KAWE’s capacity as the leading organization providing comprehensive services for people with epilepsy, the Board of Directors focused on resource mobilization for sustainability. One KAWE staff member attended a training on local resource mobilization with support from the Kenya Community Development Foundation. After the training he then briefed the other staff and developed a plan to mobilise resources required for implementation of KAWE’s activities. The Board of Directors also finalized acquisition of office space which was initiated in 2015. To ensure this asset is utilized well and also contributes to cost of services provided, KAWE staff have occupied only part of the space the larger part occupied by a tenant. Not having to pay rent has also cut down on KAWE’s administrative costs.

2 other members of staff were trained on Communication and Presentation skills including a short course on Media engagement techniques. These are valuable skills to improve how we pass on information to our varied audiences using a variety of media including our website, social media platforms, print and mass media.

KAWE Clinician Judy Kariuki attending patients at Kambioos

The Caravan at a market centre in Bungoma County

Tedi Oburu at the Community Health Workers Show

Nairobi Governor Dr Kidero greets KAWE staff

Chapter spotlight number 3, South Africa

EPILEPSY SOUTH AFRICA CELEBRATES 50 YEARS!

By Marina Clarke

On 29 September 2017 Epilepsy South Africa celebrated our 50th anniversary. This marked the start of a year-long celebration. Until the 1960's the South African National Council for Mental Health delivered services to persons with epilepsy. Dr AV Bird from Johannesburg presented a "Blue Print on Epilepsy" to the National Council for Mental Health which led to the establishment of a "Division of Epilepsy" during October 1963. It soon became clear that the "Division for Epilepsy" needed to function as an autonomous national council and in October 1964 this Division became a steering committee.

Establishment of Epilepsy SA

A national conference on epilepsy was held in Pretoria from 27 to 29 September 1967 with the South African National Epilepsy League (SANEL) founded on 29 September 1967. An Executive Committee was elected with Mr WH Barnard as chairman and Dr H Moross as vice-chairman and on 1 June 1970 Mrs A de Villiers was appointed as the first National Director with an office in Pretoria. At an Extraordinary General Meeting held on 20 April 2002 in Durban the name and logo of SANEL changed to EPILEPSY SOUTH AFRICA. The National Chairperson was Rowena Stewart and the National Director Kathy Pahl.

Who is Epilepsy South Africa and what do we do?

Epilepsy South Africa is the only national non-profit organisation in the country focusing specifically the needs of persons with and affected by epilepsy while also providing services to persons with other disabilities. While the organisation grew from a strong social work background our vision today clearly shows the change in focus: *Epilepsy South Africa: Igniting the flame of potential*. Our current mission is to promote human rights and an inclusive society for persons with disabilities, primarily persons with epilepsy. As such, our work is grounded in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) while we also contributed to the development of the South African White Paper on the Rights of Persons with Disabilities (WPRPD) and the African Disability Protocol (currently in its final stages). Our services are grouped into three main areas:

A glimpse into our work

 *Agricultural project in rural Free State*	 *Packaging contract in the Gauteng protective workshop*
 *Residential care centre in Mpumalanga*	 *Skills development training (furniture manufacturing) in Cape Town*

Candle lighting ceremony in Knysna (Western Cape) in support of International Epilepsy Day

Woodworking factory in Cape Town

Epilepsy awareness and education workshop in rural Eastern Cape

Our organisational structure

Epilepsy South Africa is one of the smaller disability organisations in South Africa with a National Office based in Cape Town and six Branches:

The organisation is governed by a National Board and National Executive Committee. Our current National Chairperson is Dr Phindile Mnguni (a radiologist by profession), our Vice-Chairperson is Mr Tim de Villiers (a traffic engineer with epilepsy) and our Treasurer is Ms Sibonokuhle Mbewe (an entrepreneur). Our current National Director is Marina Clarke who also serves on the IBE Africa Regional Executive Committee and the IBE Education Commission.

The 50 for 50 Campaign

The Campaign was inspired by international cricketing legend, Jonty Rhodes who has been a vocal ambassador for persons with epilepsy. His achievements have inspired many and we are drawing on this to challenge South African sportsmen and women to donate

ZAR50 (approximately US$4) for achieving their own magical "50's". More information will be provide in the next newsletter.

Other events on our calendar include:

- 21 March 2018: Celebrating Human Rights Day to commemorate the sacrifices to attain democracy and realise the rights of persons with disabilities;
- 25 May 2018: Tekkie Tax Day, a South African national fundraising campaign benefitting five non-profit sectors (animals, bring hope, children, disability and education);
- June 2018: Linking our Nicholas Project (a youth development initiative) to heighten epilepsy awareness among young people during National Youth Month;
- 18 July 2018: Spending your 67 hours on Mandela Day to visit our centers and residential facilities in various provinces offering a home to one of the most marginalized groups in South Africa; and
- August 2018: Celebrating women and girls with epilepsy during National Women's Month as the pillars of strength in their families.

You can contact Epilepsy South Africa

- Tel: +27 21 556-3753
- Email: nationaldirector.no@epilepsy.org.za
- Facebook: https://www.facebook.com/epilepsy.southafrica/
- Website: www.epilepsy.org.za

A BIG THANK YOU *to Epilepsy South Africa for supporting the Malawi petition. You can find the petition here: http://www.neurology.org/site/includefiles/petition_malawi.pdf*

1st International Workshop on Onchocerciasis – Associated Epilepsy (Oae2017), held on 12-14th October, 2017, Antwerp, Belgium.

Report by Antony Zimba, IBE Treasurer

Nodding syndrome is a poorly understood neurological disorder that has been associated with infection with onchocerca volvulus and is thought to be part of the spectrum of the onchocerca Associated Epilepsies. Onchocerciasis occurs mainly in tropical areas. More than 99% of infected people live in 31 countries in sub-Saharan Africa. It is also found in six Latin America and in Yemen in the Arabian Peninsula.

The disease is spread by the bite of an infectious blackfly. When a blackly bites a person who has onchocerciasis, microscopic worm larvae called microfilaria in the infected person's skin enter and infect the black fly. The larvae develop over two weeks in the fly to a stage that is infectious to humans. Once the humans especially children are infected neurological symptoms start manifesting. Some of the symptoms seen are seizures, stated growth etc.

Among the countries where this disease was found is Uganda. Because of this discovery, in 2012 the Ugandan Government declared an epidemic of nodding syndrome (NS) in the Northern district of Lamwo, Pader and Kitgum. This region also has high burden of other forms of epilepsy.

The Nodding syndrome recently was also identified in other parts of Africa such as Tanzania, Congo DR and Sudan and many other Sub- Saharan countries.

In order to help the affected countries tackle this problem, the Global Health Institute, University of Antwerp, together with other International organizations sponsored the 1st International workshop on ochocerciasis. The workshop was held from 12th -14th October 2017 at the Global Health Institute University of Antwerp in Belgium. 94 participate from the following countries attended the workshop; Cameroon, Belgium, France, DR Congo, United Kingdom, Uganda, United States of America, Austria, Netherlands, Burkina Faso, Ethiopia, Tanzania, Switzerland, Germany, Central African Republic, Sudan, Guinea-Bissau, Japan, Luxembourg, Kenya and Zambia. Form Zambia I was invited to attend the work shop to represent IBE Africa region as outgoing Vice President and also represent Zambia.

The aim of the workshop was to update the Researchers, health workers and organizations working in the field of Neurology and other related health disciplines with the latest knowledge about the different clinical presentations of epilepsy observed in onchocerciasis endemic regions. It is clear that there is a high prevalence and incidence of epilepsy in many onchocerciasis endemic regions where onchocerciasis is sufficiently controlled. This problem has been recognized for a long time in many Sub-Saharan African Countries, but the problem has never been addressed in a comprehensive multidisciplinary way. During the workshop it was felt that the burden of disease caused by OAC looks to be considerable but the exact magnitude still needs to be determined.

It was also felt that there is a need for action because the psychosocial and economic consequences of epilepsy in many remote areas of OAC regions are considerable. There is no need to wait until the exact path physiological mechanism of AOC is known to take action.

The workshop therefore passed the following resolutions:

1. To compare data from different onchocerciasis endemic regions
2. To explore other regions which are not AOC endemic areas but have high prevalence of epilepsy and foster proper epilepsy management.
3. To explore knowledge, attitudes and practices of health care workers involving different sectors of health care
4. To Establish an OAE policy plan, such which will need to be pilot tested and evaluated.
5. To put OAE on the agenda to public health officials, International Organizations and on the list of funders
6. Establish partnership between researchers, WHO, affected communities, advocacy groups, Ministries of Health, non-governmental organizations, the pharmaceutical industry and funding organizations.

Committee meeting during Onchocerciasis works

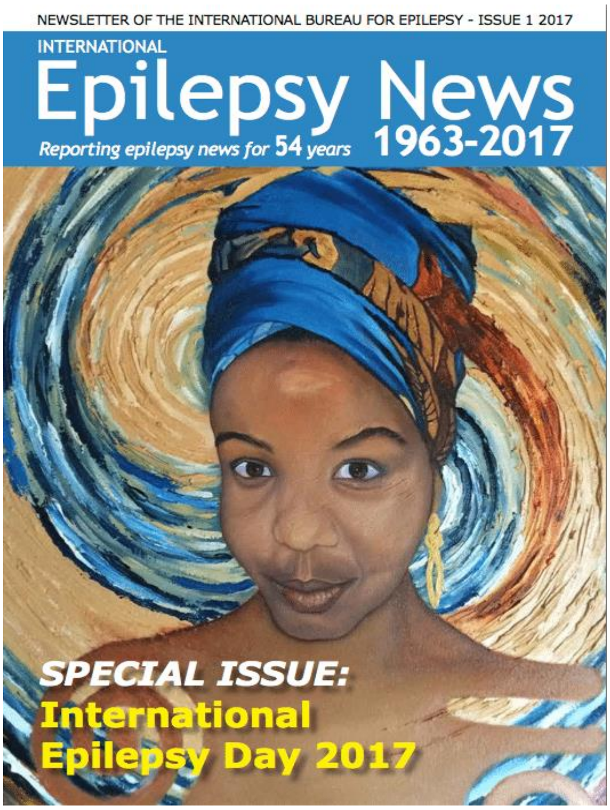
It was the hope of the workshop organizers and participates that, the AOC Alliance which was formed at the close of the workshop, will realise the ultimate goal of preventing children from developing OAE and considerably improve the quality of life of people and families affected by this disease.

Interview with Lungelo Dube, photography winner 2016

1. **How does it feel to make such an achievement?**
   To achieve something like this, feels great! It's one of the best feelings I've ever experienced in my life. This achievement marks as a golden creative milestone that's deeply etched into my creative reservoir, so I'm truly humbled.
2. **How did you celebrate your win?**
   I haven't 'officially' celebrated the win. However, I've been really anxious to do so since I received the good news. But as far as celebrations are concerned, I decided to celebrate by going on a shopping spree for more canvasses and oil paints that made me really happy too. That counts, right?
3. **What inspired you to draw this piece of art?**
   There are multiple elements that played a significant role in the creation of the painting (it'll take a couple of pages). One of them, which is how I see life as beautiful, naturally rich and full of treasures which are waiting to be found by us, we just need to gravitate ourselves towards these treasures. With that being said, the main inspirational drive to create this piece was the subject herself. I absolutely admire how she freely expresses herself and throws herself at life, as if it was the last time she'd be doing so. This calculated playfulness and attitude towards life, (often misconceived as carelessness & naivety) I see as optimism without foolishness, and I think it's one of the fundamental intrinsic keys of finding formerly spoken of treasures and living life to its fullest.
4. **How would you describe the meaning of this poster in your own language?**
   Buhle lobungempela, abukaleki ngemagama. – Which translates to...
5. **How would you describe the meaning of this poster in English language?**
   "True Beauty cannot be measured with words."
6. **What words of advice do you have to other people who want to enter this competition?**
   Have fun guys! Consider competing against yourself. You can learn to become the best version of your own artist that you have ever been and then learn to surpass that. Only then, I believe you truly win as an artist. Best of luck to everyone! But most importantly of all, express yourself and have fun.
7. **What words of inspiration would you give to people with epilepsy?**
   I understand what it's like to have epilepsy. I too have had a couple of bouts. I also have family and friends who are epileptic. So I understand. You are not alone. Hey, so what if you have epilepsy? It's a part of who you are. It's yours, own it and embrace it! Take your gift and make full use of it. Refuse to compromise or feel like you can't participate in the joys of living. You can live a normal life just like everyone else and do the things that make you happy! You're one of the most courageous people I know. You know what else? Epileptic people are highly creative. Prince had epilepsy. I wonder if we can stop referring to people diagnosed with epilepsy as 'People with epilepsy or the disease of epilepsy? Could we perhaps be called 'creative sparks'? What do you think?
8. **Are you working with the Association in your country, if so what do you like doing most?**

Unfortunately no, I would love to though (One day). If I did, I'd probably enjoy doing research, mentor art to children who are 'creative sparks' and contribute to the community with solutions of ways to progressively circumvent living with epilepsy with ease, like a 'normal' person and minimise bouts. Essentially, help the healing of people living with epilepsy.

9. **Tell us about Swaziland before you go?**
   Sure! The Kingdom of Swaziland (eSwatini) is a beautiful landlocked 'exotic island' filled with peaceful, friendly & welcoming people.
   We are a people who love and pride ourselves in our culture. Our lands exude health, the rivers in Swaziland flow with majestic might; thus, Making Swaziland a great place for outdoor hiking adventures. There are many ways in which to have a truly authentic Swati experience and enjoy your stay. What I love most about Swaziland, is its subtlety when it comes to bridging the gap between Urbanisation, the digital revolution and Nature. A fine balance; It's truly a remarkable country. Swaziland is also Africa's absolute last monarchy. You should come for a visit if you haven't yet. You'll love it here!



10. **Do you have anything else to say?**
    Absolutely! I'd like to take this opportunity to thank you for your existence and being part of an incredible movement towards raising awareness to the rest of the world about the existence of people living with epilepsy. This makes all the difference, because, this brings hope and strength. To know that wherever we may be scattered around the world, more people are acquainted to this and have some kind of knowledge about epilepsy and know how to act accordingly should anything happen. So, to have this kind of support, gives comfort. I hope in the future, we all live in a utopia with a great balance with nature, free of illnesses and fear. Not just concerning epilepsy, but everything that hinders our true potential as humans to live free, expressive full lives. **Picture insert: the photo that won Lungelo a price.**

Points from video meeting with IBE President and Executive Director

On 6 December 2017, Jacob had a video meeting with Martin and Ann. Below are some points from the meeting:

Points:

1. Chapters were encouraged to be active.
2. The IBE's main project is going to focus on young people with epilepsy. The project is called EpilepsyNext. We were encouraged to be fundraising in our region and to develop programs that support EpilepsyNext within our contexts.

3. We were encouraged to build networks with experts and other people visiting Africa to promote epilepsy work.
4. Lesotho applied to become the 20th African chapter. The application is being considered.
5. New committee member - Lisk Durodami is now a member of our AREC.
6. Young person with epilepsy in AREC (generally 18-35 years) - It was also suggested that we have a young person with epilepsy in the AREC. AREC thinks this is a very good idea.

Please contribute to the newsletter

We are calling for chapters, their groups and members to contribute to the newsletter. Each month we are going to do a chapter spotlight. Be the first chapter to appear in our November issue of the Epilepsy Africa newsletter.

We are on social media, join us today

You are encouraged to join these social media groups, and participate, follow, like posts, and comment regularly:

- WhatsApp Group for people with epilepsy and significant others: +260977789042
- WhatsApp Group for professionals interested in epilepsy: +260977789042
- Epilepsy Africa Facebook group: https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts
- Email list: We have three email lists – for social issues, for professionals and for associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrica@gmail.com.
- Our Twitter account is here tweet to us: @EpilepsyAfrica

Life is Beautiful – Photography Competition to celebrate International Epilepsy Day 2018

To celebrate International Epilepsy Day 2018, IBE is delighted to announce an international photography competition for all ages with the theme ‘Life is Beautiful’ – that life is beautiful despite a diagnosis of epilepsy; that life is beautiful when enjoyed with family and friends; or that nature shows us how beautiful life is!

PRIZES **Under 12 years** 1st Prize of US$500 5 runners up prizes of US$100 each **Over 12 years** 1st Prize of US$500 5 runners up prizes of US$100 each. **https://epilepsy.org/life-beautiful-photography-competition-celebrate-international-epilepsy-day-2018/**

Resources

- To create your own online petitions visit this website - https://www.change.org/
- To access this newsletter - https://www.ibe-epilepsy.org/epilepsy-africa-newsletter-3-november-2017/
- IBE Life is Beautiful photo competition https://epilepsy.org/life-beautiful-photography-competition-celebrate-international-epilepsy-day-2018/
- WHO resolution on epilepsy: https://www.ibe-epilepsy.org/who-resolution-on-epilepsy-approved-at-world-health-assembly/ or https://www.ibe-epilepsy.org/wp-content/uploads/2015/05/NewResolutionText.pdf

Opportunities

Youth Projects Funding is back again this year!

Youth project - we are going to seek funding for the youth project that the previous committee used to run. We will prioritise projects that promote epilepsy advocacy. Small but effective projects that we could trace, document and measure outcomes easily. For example, preparing a petition to Parliament or arranging a meeting with Health Minister or doing an epilepsy advocacy walk etc. To apply, please use application form at the end of this newsletter.

New committee member

Last month we said we were in the process of identifying two members to join the committee. The good news is we already have one. Dr Lisk Durodani agreed to join the committee. We wish to welcome him and thank him for his commitment. We still need another one. We are using this opportunity to bring in members from regions that are not represented – West and East Africa.

Call for young person with epilepsy to become a committee member

We are seeking an enthusiastic young person with epilepsy to join the AREC committee. If you have epilepsy, and you are between 18 and 30 years, please write to us telling us why you are the best candidate. This is a perfect opportunity to develop your leadership skills. Your letter must not exceed one (1) typed page. Email to: edycs.org@intnet.mu Subject: Youth committee member application.

Advocacy Project

As the African Regional Executive Committee (AREC), our work is going to focus on advocacy. Later we will develop programs for income and services (infrastructure and treatment). Below we outline the advocacy project that we are already seeking funding. The AREC represents 19 epilepsy associations that are all affiliated to the IBE. These associations represent 18 countries out of 47 countries in the WHO Afro Region. AREC has contacts in 12 other countries without associations. The AeA program seeks to promote the implementation of the WHO Resolution on Epilepsy through a four year advocacy project spearhead by mostly young people with epilepsy with the support of epilepsy associations where they exist. The AREC will manage the project. Thirty (30) countries will be targeted in the first phase – these countries will include 18 countries with associations and 12 with contacts.

Despite adoption of the WHO Resolution on Epilepsy in 2015, most African countries do not have plans to implement it. The AeA project seeks to advocate the implementation of the WHO Resolution in African countries through the identification, capacity building and support of 30 young people with epilepsy. The advocacy seeks to ensure that epilepsy is recognised as a health and social priority and that governments provide resources for the development and implementation of national epilepsy plans. Epilepsy associations will help scale up the project. However, research carried out in 2016 by the AREC show that epilepsy associations are severely constrained, hence the need for capacity building to strengthen their capacity. In summary, the advocate project has these advantages:

1. It fits within IBE's EpilepsyNext project that seeks to empower young people with epilepsy.
2. It fits within the Global outreach project (a continuation of the Global campaign Against Epilepsy).
3. It advocates for government funding of epilepsy programmes that is the most sustainable solution in Africa.
4. It addresses the gaps identified by the AREC in their 2015/6 research on the situation of chapters in Africa and consultations done in 2017.
5. It is based on the WHO Resolution on Epilepsy.
6. The project provides room for fundraising at a regional level and also allows countries to fundraise for resources to use in their countries.
7. It has several outcomes, some listed after the table.
8. Projects are going to be implemented in all chapters in the region.
9. The 30 advocates who will be trained first would train others in their countries.
10. The project is suitable for both young people and adults with epilepsy as well as professionals and non-professionals.

Activities and Targets

Year	**Activities**	**Targets**
1	Development of advocacy training manual and other advocacy tools.	Manual, branded bags/shirts/bags & website.
	Identification & training of advocates.	30 advocates trained online.
2	Training of associations in advocacy, fundraising & management.	30 associations trained.
	Supplying associations with advocacy material.	30 associations receive advocacy material.
	Promoting adoption of WHO Resolution.	30 countries and regional institutions like African Union adopt the Resolution.
3	Advocating for implementation of national epilepsy plans.	30 countries develop national epilepsy plans.
	Formation of a network of epilepsy advocates in Africa.	Composition of the network of epilepsy advocates.
4	Advocating for implementation of national epilepsy plans.	Support to advocates and associations.
	Advocates symposium.	30 advocates attend symposium.
	Evaluation of program.	Consultant, and financial reports.
1-4	**Other costs:** Incentives for advocates for transport, internet, courier, phone & post & Travelling- AREC & IBE/ILAE leaders to support projects.	

Other anticipated outcomes:

1. Articles published in refereed journals.
2. Model national epilepsy plan identified.
3. Project presented at three epilepsy congresses.
4. Yearly program reports produced.
5. New IBE/ILAE chapters

Conclusion

The advocates program presents an opportunity for young people with epilepsy to use their energy to push their governments to develop and implement national plans in line with the WHO Resolution. The project is an innovative approach that is cost-effective. By targeting individual advocates, this presents an opportunity to reach more countries, while at the same time building the capacity of associations to strengthen advocacy efforts. It is our hope that partners are going to support this project to help us reduce the several challenges faced by 10 million people with epilepsy on our African continent.

Until the next issue, happy happy everyone! Please print the poster on the next page and share with your members.

In the next and future issues

In the next issue we are going to talk about

- Information about IBE's exciting Epilepsy Next project.
- Message for association treasurers
- Information about IBE Taskforces.
- Information about IBE's exciting Epilepsy Next project.
- Chapter spotlight (If your chapter is willing to appear in the next newsletter, please email Betty).
- Understanding epilepsy in local languages.
- The 50 for 50 Campaign in South Africa.

Poster

See next page. Please print, display on your notice boards and distribute the poster.

TOPICS FOR TRAINING AND TEACHING

Most epilepsy associations conduct training workshops and teaching classes. Here is a list of topics that you could use to select and develop courses for doctors, nurses, other health workers, social workers, parents, people with epilepsy, government workers, churches and community workers.

1. Current social science research evidence
    a. Review of social work evidence
    b. Recent psychosocial studies
    c. Policy gaps and evidence utilisation
2. Social management of epilepsy
    a. Employment and epilepsy
    b. Epilepsy as a disability
    c. Counselling and psychosocial support
    d. Fighting stigma and discrimination
3. Managing epilepsy organisations
    a. Advocacy skills for people with epilepsy, carers and service providers
    b. Human Resource Development for Epilepsy
    c. Starting and running a support organisation
    d. Participation and self-representation of people with epilepsy
4. Epilepsy in resource limited settings
    a. Fundraising and resource mobilisation
    b. Public financing and advocacy
    c. Use of social media for awareness, training and epilepsy management
5. Emerging Issues on Epilepsy
    a. Human rights
    b. Young people with epilepsy
    c. Women with epilepsy
    d. Complementary treatments/Traditional treatments
6. Individual stories/experiences
    a. What it means to live with epilepsy
    b. What it means to have a child with epilepsy
    c. Improving doctor/health worker/patient interaction
7. Childhood epilepsy
    a. Learning and behaviour problems that are associated with epilepsy in childhood
    b. How children understand epilepsy
    c. Nurturing resilience and self-mastery of epilepsy
8. Treatment gap/Improving quality of care
    a. Side effects
    b. Using technology (telehealth) to improve awareness and communication
    c. Improving access to treatment/Closing the treatment gap

Do you have any other topics to suggest, please email us at ibeafrica@gmail.com.