



EPILEPSY AFRICA NEWS

Issue 21

November - December 2019

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



Cover Photo: Participants at High Regional Multi-Stakeholders Meeting in Mauritius

Contents

- Editor's Message
- Article of Interest: Rwanda – More Doctors Trained
- Review on the Year 2019 – Grace N. Moyo, Zimbabwe
- Highlights of AREC Visit to the Kingdom of Eswatini
- ARADI Regional High Level Multi Stakeholders Meeting
- EDYCS Award
- Leader of the Month

About this newsletter: Editorial team: Action Amos; Youssouf Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** bi-monthly **Distribution:** Email and other social media. **Email contributions to** ibeafrika@gmail.com or amos_action@yahoo.co.uk Enjoy your reading!

How to join us:

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 associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrika@gmail.com. You can also catch up on missed issues on <https://www.ibe-epilepsy.org/publications/regional-news/> and www.epilepsyafrika.org

CHAIRPERSON & EDITOR'S MESSAGE

It is with excitement that we are closing this year 2019. AREC is excited with new and potential that this region will working on in 2020. As was promised in the last edition of our newsletter we indicated that we will be having a pilot situational analysis in Rwanda and Eswatini and we are excited to inform all that the data collection was completed. We want to than the chapters that were involved. We are hoping to replicate this with other chapters soon.



A team from AREC was privileged to travel to Eswatini to meet with the Chapter as well as work on the upcoming African Epilepsy Fund. We are excited to inform you that we are now on the verge of full registration with the identification of the Board and Patron including an AU Ambassador who is Past President of one of the African counties already identified. We are excited to inform you that the Kingdom of Eswatini has offered to host the Trust Fund with full government support. The full report is contained in this newsletter. Our newsletter will contain feedback that has been received from members on the establishment of the Trust whose sole purpose is to support all chapters in capacity building, economic empowerment and educational grants.

In gearing for 2020 we are excited with negotiations that are on the table to develop an Inclusive Epilepsy Advocacy Toolkit. All chapters will be involved in the consultations of its content with a smaller team having to work on it later. Additionally, negotiations on the Promising Strategies Fund are on the table and by the time you are reading this edition due to publishing delays a call is now out!!!! There is an increase now in funding to the tune of \$20,000 to be awarded to Chapters with successful proposals.

We would want to take this opportunity to celebrate award winning Chapter Leader Mr Youssouf Noormamode from Mauritius who was awarded a Regional Leadership Award. We say “Bravo!!!! We look forward to your continued advocacy work in IBE and Africa. As additional caps, the IBE Vice President and AREC Chairperson, Mr Action Amos and the AREC Vice President Mr Youssouf Noormamode was elected Vice President with Action Amos elected as a Board member were both nominated to sit on the Board of Africa Disability Alliance. The term of office will be five years.

We take this opportunity to thank all that have stood with AREC and its Chapters in 2019 especially IBE Executive Management, Band Foundation and African Disability Alliance. Without our Chapters we would not be where we are as we gear up for 2020.

Action Amos
IBE Africa Vice President

*If you have a story you'd like us to consider for publication, please contact: ibeafrica@gmail.com,
amos_action@yahoo.co.uk*

ARTICLE OF INTEREST

Rwanda: More Medical Doctors Trained at Detecting and Treating Neurological Disorders in the Early Stages

3 OCTOBER 2019

The New Times (Kigali)

By Michel Nkurunziza

Medical doctors from district and referral hospitals in Rwanda are receiving training on the early detection and treatment of cancer and neurological disorders as a mechanism to address the current small number of specialists in neurology and oncology in the East African region.

The training is part of a four-year programme funded by the East African Development Bank (EADB) and implemented by the British Council in collaboration with the Royal College of Physicians and the Rwandan Ministry of Health through Centre Hospitalier Universitaire de Butare (CHUB).

David Odongo, Acting Head of Business at the East African Development Bank-Rwanda Office, said that they have been funding the medical training programme since 2016.

"EADB provides resources to various partners including the British council and we facilitate the Royal College of Physicians across the region where there is generally a lack of specialists in the field of neurology as well as oncology. What the bank is trying to do is to increase capacity in early detection and treatment. Our target is 600 doctors over a four-year period. We wish this number could go higher but this is what the resources will allow. However we feel it will have a significant impact to start a process where we can train even more doctors," he said.

According to Esperance Uwamaliya, Programmes Manager at the British Council, the current neurology clinical training course, being the third cohort, is benefitting 20 Rwandan medical doctors from different hospitals.

The first day of the training focused on history taking and examination, headaches, brain tumours, nerve and

muscle disease, movement disorders, brain infections, epilepsy, pediatric conditions, stroke and dementia among others.

With 30 doctors trained previously, the number has now increased to 50 trained medical doctors.

Uwamaliya said that the trained medical doctors will build strong knowledge and skills in the early detection and treatment of neurological disorders in their respective hospitals and also be able to appropriately refer cases to referral hospitals that need specialized professionals.

"The training has a positive impact as medical doctors are learning and acquiring new knowledge. They will be able to carry out preliminary checking, interpreting symptoms and understand the condition, before treating or referring the patient. They are still general professionals but in the end they can specialize in neurology." Uwamaliya said.

She noted that once the general medical doctors do suitable referrals, it will become easier for specialists at referral hospitals to treat patients.

She said that neurological cases are on the rise and previously weren't really spoken about.

"Many used to think they are suffering from witchcraft. Many patients seek treatment when the disease has reached further stage since there was no early detection. Now people are becoming more aware and getting knowledge about the disease. Trained doctors are needed in early detection and treatment," she said.

The British Council, she said, was selected as a partner to run the programme as the UK education and medical environment is known to be advanced in neurological disorders and cancer treatment. *Read the [original article](https://allafrica.com/stories/201910030070.html) on <https://allafrica.com/stories/201910030070.html>*

We have been greatly blessed to have been part of the International Bureau for Epilepsy in Africa (hereafter referred to as IBE Africa) in the year 2019. The year has come to an end and we are welcoming the New Year 2020. As the New Year begins it is imperative to reflect on the things that took place during 2019 as we prepare for the year 2020. The year was activity filled with lessons learnt and it is our hope that as we reflect on those we will be better prepared for a new year as a region. Only a few notable activities will be reflected on in this article. It is notable that indeed, the year was a good one as shall be seen in this report.

Among other things, we wish to applaud Zimbabwe and Namibia among other countries for the work done to sensitise their respective countries on issues concerning epilepsy. In Zimbabwe, the Epilepsy day was celebrated by creating awareness through going on air on one of the radio stations in Zimbabwe, which is National FM. Also, on the 16th of February, they also had an interview on ZBCTV on the programme 'Young, Gifted and Talented'. Namibia participated in a workshop with the Namibia Statistics Institute on questions for people with disabilities during the census and another one with Ombudsman on participation in politics for people with disabilities. We are

grateful that people with disabilities in Namibia can vote thanks to that workshop.

A few more countries, namely Cameroon, Sierra Leone and Rwanda, were also selected to receive financial assistance to carry out Young people with Epilepsy Support (YES) projects and hopefully the projects are going on well. These projects are meant to help people with epilepsy to be able to support themselves instead of being dependent on other people.

It is in this year that the 4th African Epilepsy Congress was held in Uganda and a lot of lessons were learnt and shared to respective Chapters in our Region.

However, the year had its own problems which among other things included the economic challenges faced by the different countries in IBE Africa. Despite those challenges we managed to sail through the year with the help of the Almighty.

In conclusion, we thank all the people who made positive contributions for the success of this year. We encourage each other to continue working hard for the success of IBE Africa. God will surely reward us. We thank everyone for a job well done and we wish you a very successful year ahead. Keep sending reports and stories to be included in the AREC Newsletter, making known the activities of each Chapter

Highlights on AREC visit to the Kingdom of Eswatini

Background:

Following an invitation from the Eswatini Epilepsy Association (EEA), a visit to the Kingdom of Eswatini was undertaken for two important issues, namely the proposed establishment of an African Epilepsy Trust Fund (AETF) and to check on progress of the Africa Epilepsy Advocacy (AEA) Project. The **IBE Vice President/AREC Chairperson, Mr. Action Amos** and **AREC Secretary Ms. Betty Barbara Nsachilwa** arrived in Eswatini on 13th November, 2019 and lodged at the Summerfield Resort. The visit comprised discussions with His Royal Highness Prince Bandzile, the Honourable Minister of Health, World Health Organization Country office, the Epilepsy Association of Eswatini and monitoring the Band funded project.

Success:

The trip was successful as all the meetings were held as planned and the way forward mapped for the African Epilepsy Trust Fund.

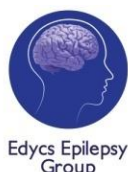
The team saw that the Advocacy Project was of utmost importance to the local Chapter and they were making strides to ensure success of the project. **(Full report already published in the IBE IE News)**

Meeting with His Royal Highness Prince Bandzile (in traditional Wear in the middle) and Hon. Minister of Health



Meeting at WHO, Eswatini Office





ALLIANCE FOR RIGHTS - AFRICA TOWARDS DISABILITY INCLUSION (ARADI) REGIONAL HIGH LEVEL MULTI STAKEHOLDERS MEETING – BY YOUSSEUF NOORMAMODE, AREC VICE CHAIRPERSON

The regional high level multi-stakeholders meeting was organised by EDYCS Epilepsy Group and took place on **Monday 16 December 2019** at the **Voilà Hotel in Bagatelle, Mauritius**. The meeting was attended by local and regional key persons in the disability sector. Among members present at the meeting were six panelists, including the Honourable Minister of Social Integration, Social Security and National Solidarity (Chief Guest), the Commissioner of the African Union Commission on Human and People's Rights, and the Honorary Consul of the Republic of Cote D'Ivoire. There were also some thirty four attendees/participants at the meeting.



INTERVENTION OF PANELISTS

The intervention of panelists can be summarised as follows:

1. Paramasiva Chengan, Moderator

He addressed the audience and welcomed all guests present while observing established protocol and presented bouquets to the following guests as a token of EDYCS Epilepsy Group's respect and appreciation:

The following were the guests:

- Hon. Fazila Daureeawoo, Chief Guest, Minister of Social Integration, Social Security and National Solidarity;
- Lefhoko Kesamang, Foreign delegate, African Union Commission
- Action Freddy Amos, Foreign delegate, International Bureau of Epilepsy
- Razaka Ralphine Manatenasoa, Foreign delegate, Réseau National des Femmes Handicapées de Madagascar (RNFH MADA)

The moderator then explained the rationale behind that initiative and the importance of the Africa Disability Protocol (ADP) and its ratification. He further explained the purpose of the regional meeting and wished everyone a fruitful meeting. He introduced Mr. Youssouf Noormamode and invited him to address the audience.

2. YOUSSEF NOORMAMODE, PRESIDENT OF



EDYCS EPILEPSY GROUP

Mr Noormamode covered the following points:

- There is so much that has been achieved in the field of disability but still a lot of people living with disabilities (PWD) are facing challenges which are affecting their lives;
- This new protocol (ADP) is shedding light on invisible disabilities (which is going to be part of a new framework that will help to shape Governments' agendas and bring all types of disabilities into the limelight);
- This protocol is for Africa and it is very important that all governments ratify this protocol, as once it is ratified other instruments will come into play such as the Model Disability Law (MDL) and the National Bill on disability (which is a bill in line with all articles that appear on the new charter on persons with disabilities); and
- This high level meeting has been made possible through funding by EU and CBM.

He expressed that his wish as the new Vice President of the Africa Disability Alliance (ADA) is that the ADP be ratified and the MDL be established, so that PWD enjoy all their rights in line with the protocol. He

further mentioned that although Mauritius is such a small country compared to other African countries, the country's achievement in terms of disability, in the absence of a disability bill, is quite impressive. Lastly, he thanked the Honourable Minister for attending the meeting despite her tight schedule and wished everyone present a fruitful meeting.

3. HON. FAZILA DAUREEAWOO, CHIEF GUEST, MINISTER OF SOCIAL



INTEGRATION, SOCIAL SECURITY AND NATIONAL SOLIDARITY

Hon. Daureeawoo welcomed all regional delegates and addressed the audience through a key note address and covered the following points:

- The needful is being done by the Ministry to push the disability bill to Parliament at the soonest;
- The hard work done by EDYCS Epilepsy Group and the ADA, through different initiatives (regional meetings and workshops), is commendable and is paving the way to equity. The cause is a worthy one for Mauritius and Africa at large;
- Since the ratification of the UNCRPD the following measures have been adopted by the Government:
 - An increase in the Basic Invalid Pension (BIP). This year only the BIP increased from Rs 6,210 to Rs 9,000 monthly;

- Children with disabilities under the age of 16 who were previously not eligible for any BIP are now eligible to receive the BIP;
- The Special Education Needs (SEN) educational framework has been improved through the setting up of a Special Needs Authority, whose objective is to facilitate the design and implementation of SEN policies in line with international conventions on the rights of the child and on the rights of PWD;
- The Government has taken measures to ensure that all new buildings cater for the physical accessibility of PWD;
- In terms of transportation, semi-low floor buses have been made available. In addition, transport fares are reimbursed for children with disabilities enrolled in primary, secondary and tertiary education;
- Free home medical care are provided for children with disabilities;
- People living with disabilities are provided with free parking coupons, have duty free facilities and benefit from reduced rates while travelling via Air Mauritius; and
- The Government also provides assistive devices (wheelchair, glasses, and hearing aids) at no charge to PWD.

Furthermore, the Hon. Minister announced that a Special Committee dealing with disability issues and the rights of PWD will be set up next year. She added that the Government is fully committed to defend the rights of PWD and that the cooperation of NGOS, the private sector and the society at large is crucial for this endeavour. Lastly, she thanked everyone present for their dedication to this cause.

The Minister presented certificates of appreciation to two Disability Champions, namely, Mr. Lefhoko Kesamang, from the African Union Commission, and Mr. Action Freddy Amos, from the International Bureau of Epilepsy, for their outstanding work in the field of disability worldwide.



PRESENTATIONS

1. **First Presentation: Mokshadha Toolsee, Programme Officer under ARADI Project at EDYCS Epilepsy Group**, gave a brief presentation on the ARADI Project, which outlined, *inter alia*:
 - The ADA as a technical agency and its programmes and projects;
 - The current programme being implemented by ADA (ARADI Project);
 - The objectives of the ARADI Project which is a continental disability oriented strategy programme of ADA;
 - A brief description of the Action;
 - The objectives of the advocacy regional training sessions organised by EDYCS Epilepsy Group and the ADA;
 - Some important figures pertaining to the ADP; and
 - The upcoming activities of the ADA, including training on the different provisions or articles of the ADP.

Mr. Youssouf Noormamode added the following points on the ARADI Project:

- The project started in 2017;
- There were several consultations at regional and national level. In the case of Mauritius, there were official meetings with the Minister of Gender Equality, the Minister of Justice and the Minister of Social Security, amongst others;

- Consultations with business entities were also carried out, including Business Mauritius, where the issue of accessibility to employment was raised;
- All inputs were gathered and have been sent to the AU working group;
- All key activities done were in line with the ARADI scheme of work and planned goals;
- The Project is expected to end by Jan 2020; which will hopefully be extended to allow time for countries to ratify the ADP;
- Five countries have committed themselves to ratify the protocol;
- ARADI is not the issue of EDYCS only, it concerns everyone, which is why everyone has to do their part and lobby with their governments and stakeholders;
- It is crucial to build the capacity of technical officers from different Ministries on the mainstreaming of disability and also on the ADP and the MDL. This has been planned for Jan 2020;

The presentations were followed by a Question and Answer Session and Questions 2 and 4 were interesting for this session:

Question 2:

Ms. Vandana Gooria from Down Syndrome Mauritius asked the following question: ***“Have you ever considered the voice of parents in your consultations? (E.g.. Did you conduct parents’ workshops?). They are the ones closest to children with disabilities and they know the needs.”***

Mr. Youssef Noormamode responded that the first high level workshop was done by the parents for the parents, because one cannot talk about the rights of children with disabilities without taking into account parents. Moreover, during the multi-stakeholder meeting at Le Meridien hotel, PWD and their families were invited. Throughout all the consultation process, which is still ongoing, the views and inputs of parents have to be taken on board.

Mr. Action Freddy Amos from the International Bureau of Epilepsy (IBE) Africa responded to the question by saying that the African Down Syndrome Network does consultations with parents at a regional level. In addition, he shared that a Special Committee on disability, as mentioned by the Honourable Minister Mrs. Fazila Daureeawoo in her keynote address, is a great initiative. He added that a Shadow Committee has to be set up to provide inputs to the Special Committee and that the IBE is prepared to help local institutions in that endeavour by sharing relevant documents, tools and best practices.

Question 4:

Dr. H. Reesaul from the Ministry of Health and Quality of Life, addressed the floor: *“I have been working with patients with disabilities for more than 10 years. The problem with disabled people is not their disability; it is the low esteem that they develop. **What has been done about that?** They want to participate in actions to defend their rights but they are afraid as they have developed a low esteem over time”.*

Mr. Youssef Noormamode responded to the question by saying that part of the programme of the EDYCS Epilepsy Group designed for PWD is to build their self-esteem through capacity-building programmes. Because of the stigma that they constantly face, PWD and their families are afraid of people being aware of their condition. Organisations working for the welfare of PWD are mandated to have clear-cut strategies and programmes that empower PWD to come forward and speak about their condition. Awareness sessions and campaigning are also organised to educate people on disability. Once people are educated and knowledgeable about issues of disability, a new kind of society, free from stigma, is possible.

Mr. Lefhoko Kesamang from the African Union Commission commented that during the process of ratifying the ADP, it is important that, at national level, persons and organisations in the field start engaging

everyone in the country, especially people that will be affected by the protocol. The signing of the protocol has to go hand in hand with advocacy and road shows to ensure that everyone knows about the protocol (e.g. DPOs, families, etc.). One of the most important things about disability is to know what disability is. Disability has gone through phases over the years. Before, disability was considered as 'a disease that can be corrected'. Nowadays, the definition is based on 'the social model' and the 'rights-based model'. He added that it is the environment that disables people, and not the condition they find themselves in: *"if you build a structure that is not accessible and expect a person with compromised mobility to go in and you say that it is their problem, this is not right. If we can change our attitude, everything will change. The best way to deal with issues on disability is to let PWD do it themselves."*

2. SECOND PRESENTATION: ACTION FREDDY AMOS, INTERNATIONAL BUREAU FOR EPILEPSY AFRICA



After thanking EDYCS Epilepsy Group for inviting him to the meeting and congratulating Mr. Youssef Noormamode for his election as Vice President of the ADA, he gave a presentation entitled 'African Disability led Organisations on the move to urging Governments towards the ratification of the ADP in Malawi', which outlined, *inter alia*, the following points:

- In Swaziland, PWD are not allowed to participate in public events (e.g. cultural events);

- In Malawi, persons with albinism are killed for ritual purposes and persons with epilepsy are thought to be possessed and killed;
- When the UN came up with the CRPD, it met some of the key needs of Africa but not all of them;
- We needed a protocol for our African context to take care of our own issues in Africa. The following are a few differences between the UNCRPD and the ADP:
 - ✓ UNCRPD is global but ADP is only African-focused;
 - ✓ UNCRPD focuses on human rights but ADP focuses on people and human rights, it puts the person first and then the rights follow;
 - ✓ One example is that the UNCRPD does not have provisions for persons with albinism;
 - ✓ ADP defines PWD differently, the definition is inclusive;
 - ✓ The ADP talks about harmful practices (which includes issues about superstition, religion, culture and tradition, which is unique to Africa. The UNCRPD does not talk about harmful practices;
 - ✓ ADP talks about rights but also about duties and obligations, unlike the UNCRPD;
 - ✓ It also talks about ritual killings on PWD, about issues to do with culture (e.g. the deaf culture: people who are deaf have their own culture);
 - ✓ The ADP takes measures to protect PWD but also parents, spouses and family members, as well as all the people that support them (intermediaries);
 - ✓ It also talks about the right to be free from harmful practices and the right to access justice (e.g. this is a right that enables PWD to take part in all legal proceedings); and,
 - ✓ It also includes a special article on ensuring that older persons with disability have full enjoyment of human rights.

After the second presentation the floor was again opened to questions from participants:

3. THIRD PRESENTATION: LEFHOKO KESAMANG, AFRICAN UNION COMMISSION SENIOR SOCIAL WELFARE OFFICER

Mr. Kesamang gave an overview of the African Union Disability Strategic Policy Framework, which outlined, *inter alia*:



- The African Union Disability Strategic Policy Framework has about 10 strategic areas (strategic objectives);
- The first strategic objective is about DPOs being empowered (strengthening the overall capacity of DPOs). If DPOs are excluded, there will be no progress. DPOs have experience and they are able to help Governments change the labour laws, the policies and the way governments provide services;
- The second strategic objective is about reducing poverty and enhancing economic empowerment. PWD experience a lot of poverty because they don't have access to education and thus do not possess the right set of skills and tend to be unemployed;
- Other strategic objectives include:
 - Strengthening disability-sensitive and appropriate social protection programmes and instruments;
 - Ensuring the inclusion of persons with disabilities of all ages in quality relevant education;
 - Ensuring gender equality and women's and girls' empowerment (it is important to take into account the double discrimination of women; women's movement need to talk more about women with disabilities);

- Improving access to health (The problem is not that health services are inefficient but the structures and environments are not appropriate for PWD e.g. people with physical disabilities cannot access hospital buildings); and
- Improving access to habitation, rehabilitation, and life-changing assistive devices and technologies, amongst others.

4. FOURTH PRESENTATION: YKJ YEUNG SIK YUEN G.O.S.K, HUMAN RIGHTS COMMISSIONER

Mr. Sik Yuen began by showing a video where he was interviewed by a journalist after a seminar in Rwanda. In the video, he gave an overview of the two protocols that he helped draft with the African Union (one protocol on rights of persons with disabilities and another on rights of older persons), which are essential African protocols. Moreover, he added that the Protocol on the Rights of Older Persons is a world premiere. In the video, he urged African states to ratify both protocols urgently.

He continued to talk about the progress that has been made so far and added that quite a few countries have signed the two protocols. However, for the protocols to be effective there needs to be 15 ratifications for each protocol. There was a lot of advocacy work being done for countries to ratify the two protocols and, he admitted that knowing the current Minister of Social Integration, Social Security and National Solidarity, there is a high chance of the protocols being ratified.

After the fourth presentation the floor was opened to comments from participants:

Mr. Lefhoko Kesamang stated that in October 2019, an advocacy workshop was held for government officials, who admitted that they did not know much about the protocol even though they are the ones who

have to initiate the process of ratification. He further said that it is important to empower government officials and urged participants present to assist their governments towards the process of ratification of the two protocols.

Mr. YKI Yeung Sik Yuen added that the ADP has African specific provisions that are not present in the CRPD e.g. the protection of people with albinism. Moreover, the approach used for the ADP is different from that of the UNCRPD in that the ADP does not only speak of rights, but also of duties.

Mr. Action Freddy Amos thanked Mr. Yeung Sik Yuen for his intervention and asked the following question: *“What were the best practices in the disability movement used to ensure that governments sign the protocol?”*

Mr. YKI Yeung Sik Yuen responded that there are 54 countries who signed the ACPHR, out of which, 32 attended the seminar (including Mauritius and Madagascar). During the seminar in Rwanda, Egypt promised to organise a similar seminar in their country. He added that most countries are willing to ratify the protocols but the conditions have to be right.

Mr. Lefhoko Kesamang stated that there are many factors that come into play for the ratification of a protocol to take place e.g. the leader of the country (e.g. the head of state or the king of the country) has to be agreeable to the rights of PWD at that particular time.

5. Fifth Presentation: Razaka Ralphine Manatenasoa, Réseau National des Femmes Handicapées de Madagascar (RNFH MADA)

Gave a presentation on the work currently being done by NGOs and DPOs in Madagascar and covered the following topics:

- Madagascar’s country background;
- How it all started: DPOs in Madagascar;
- Actions carried out by DPOs in Madagascar;



The creation of a platform gathering federations of DPOs and its objectives;

- The Réseau National des Femmes Handicapées de Madagascar (National Network of Women with Disabilities of Madagascar) and its main objectives, activities, networking initiatives and challenges;
- ADP ratification strategies in Madagascar; and Ramifications of a regional meeting on the ADP in Midrand, including the first advocacy activity to the Chair of Parliament in Madagascar, amongst others.

6. Sixth Presentation: Action Freddy Amos, International Bureau of Epilepsy Africa

Mr Amos gave a presentation entitled: *“African Disability Led Organisations on the move to urging Governments towards the ratification of the ADP in Malawi”*, which outlined, *inter alia*:



- The Malawi country background;
- The Malawi disability sector landscape;
- A definition of psychosocial disability/mental disability;

- The objectives and networking initiatives of the Pan African Network for Persons with psychosocial disabilities; and
- The ADP ratification strategies in Malawi.

He ended his presentation with a quote from Aristotle:
“No great man has ever existed without a touch of madness.”

Mr. Abdoola Janmamode, Manager at Compuspeed Ltd announced that a Facebook page of EDYCS Epilepsy Group is now live and that since this morning the discussions have been broadcasted live on Facebook. The floor was opened to participants willing to give their feedback on the regional meeting, which included, amongst others:



- *“A database on disability is paramount and statistics need to be updated in the field of disability”;*
- *“The importance of taking into consideration, while designing public buildings, the aspect of physical accessibility of PWD”;*
- *“The meeting was fruitful and there was valuable sharing of practices and experiences from all the resource persons”;*

CLOSING CEREMONY

Mr. Oudorao Apajee, Honorary Consul of the Republic of Cote D'Ivoire was invited to give a speech. He addressed the floor and congratulated everyone for the outstanding work in the disability

PRESENTATION OF ATTENDANCE CERTIFICATES TO ALL PARTICIPANTS

Attendance certificates were awarded to all participants.



HIGH LEVEL DIALOGUE - DECEMBER 17, 2020



High Dialogue Meeting held with the Minister of National Infrastructure and Community Development, Hon. Mahendranuth Sharma Hureeram. Mr. Lefhoko Kesamang from the African Union Commission highlighted the need for the African Disability Protocol to be ratified by Member States of the African Union and called on the Hon. Minister to provide leadership to its Ratification. A certificate of appreciation was then handed over to the Minister to thank him for his continuous support.

The delegation met with the Charge d'Affaires, Mr Tahiriniaina Sojarison at the seat of the Embassy of Madagascar, Floreal to advocate for the ratification of the ADP. Copies of the ADP & MDL and gifts were handed to Mr. Sojarison at the end of the meeting.



Welcome Reception and Press conference at the EDYCS Health Service Centre

Edycs Epilepsy Group Mauritius attributed the Africa Leadership Award



Her Excellency, Mrs. Ameena Gurib Fakim presenting the Award to Youssouf Noormamode, President Founder Edycs Epilepsy Group

Edycs Epilepsy Group was attributed the Africa Leadership Award in Healthcare & Social Care Support at the World CSR Day & World Sustainability Congress held on 4th December 2019 at the Westin Turtle Bay Resorts & Spa, Mauritius. The event was organized by CMO Global.

The event gathered hundred delegates from all over Africa comprising of business entities, civil societies and the media. The Chief Guest of the award ceremony was the former President of the Republic, Her Excellency, Mrs. Ameena Gurib Fakim

LEADER OF THE MONTH

Youssouf Mahmad Noormamode

Founder and President of Edycs Epilepsy Group Mauritius. Since 1997 till now, he is striving through Edycs Epilepsy Group to make epilepsy a national public health care priority in line with the WHO Resolution on the Global burden of epilepsy.




Achievements:

- Opening of island's first Epilepsy medical and support Center for people with epilepsy and their families by providing free epilepsy care services and establishing a Special Education Needs School for children and young adolescents with epilepsy accredited to the Ministry of Education.
- Strived and lobbied the Rodrigues Regional Assembly Commissions for Health and Education and two similar Centers were established in Rodrigues Island.
- Has served on many Committees, namely the Mental Health Task Force of the Ministry of Health & Quality of Life, the Suicide Prevention Committee of the Ministry of Social Security, the National Youth Council under the aegis of the Ministry of Youth & Sports, the NGO Trust Fund of the Ministry of Social Security, the Rehabilitation and Youth Centers Board Committee and as Honorary Vice President of the Mauritius Council of Social Services (Umbrella Network of NGOs)
- At regional level, has served as Chairperson of the IBE Africa Regional Committee, Deputy Chair of the Africa Disability Alliance and currently, AREC Vice Chairperson.

Awards through Edycs Epilepsy Group in recognition of Mr. Noormamode's outstanding contribution in epilepsy:


- Oscar de la Jeunesse Award in 1999– Ministry of Youth & Sports
- United Way Volunteers Award 2002
- Nominee Jeune Chambre Economique de Maurice AYOP 2003
- Nominee Junior Chamber International The Outstanding Young Person World Program in medical innovation 2003
- National Youth Council Youth Project Award 2004
- Man of the Year 2008 Award conferred by the American Biographical Research Institute
- Life time Achievement Award by the Mauritius Council of Youth Leaders 2009
- Commander of the Star Key of the Indian Ocean C.S.K. Insignia conferred by the President of the Republic of Mauritius Year 2009
- Africa Leadership Award conferred by World CSR Sustainability Congress.

ANNOUNCEMENTS:



PROMISING STRATEGIES 2020

STIGMA AND ADVOCACY PROGRAM
Reducing stigma and discrimination in Africa



CALL FOR LETTERS OF INTENT
Deadline Friday 17th January 2020

You are urged to apply for this year's Promising Strategies to enable your organisation accomplish the goal of reducing Stigma and Discrimination in your country.



It is also great opportunity to commemorate the International Epilepsy Day, which falls on **10th February, 2020**. ***Educate, learn and implement, thus raising Epilepsy to a plane of Acceptability!*** We look forward to receiving your reports on your activities.

Contributing to the newsletter means Continuity:

We are calling for chapters, their groups and members to contribute to the newsletter. You could share this with us:

1. Your local Newsletter
2. Your plans for 2020
3. Questions on epilepsy care
4. Photographs

Did you enjoy reading our newsletter? Please give us some feedback: **Email - ibeafrica@gmail.com**

If you have any other topics to suggest, please email us at ibeafrica@gmail.com by 20th of each month

Next Issue to feature: International Epilepsy Day Reports