



EPILEPSYAFRICA NEWS

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



Cover Picture: Participants at the Epilepsy and Seizure Disorder Management Workshop, Mauritius

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About this newsletter: Editorial team: Action Amos; Youssef Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** Monthly **Distribution:** Email and other social media. **Email contributions to:** ibeafrika@gmail.com. Enjoy your reading!

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CHAIRPERSON & EDITOR'S MESSAGE:

Welcome to this edition of Epilepsy Africa and very warm greetings to all new readers since our last new regional newsletter went out. It is with excitement that Africa welcomes two new members (Rwanda and Lesotho) to its International Bureau of Epilepsy family. Since the completion of tenure of office for our past President Dr. Jacob Mugumbate, it is with all humbleness that I join a capable team of Epilepsy leaders on the continent as the new Vice President for Africa. The year is already going by very quickly and our organization is active on many fronts in Africa. It is with joy that engagement with Africa Union was resumed and engagements by our Mauritian Chapter has seen epilepsy being recognized by the African Union as a disability. This, therefore, will enhance our effort of fighting stigma and discrimination together with others disabilities.

Africa was well represented in the General Assembly that took place in Bangkok. Significant issues for persons with epilepsy such as poverty, access to medication, employment and health were covered in the discussion that took place. We continue to advocate for change and have made efforts to engage promptly and effectively within six (6) governments under the Band Supported Advocacy Project. The project will see the targeted countries develop national epilepsy plans.

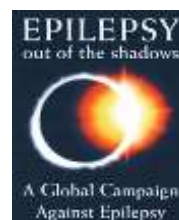
This Newsletter will be published at a time of significant change in epilepsy as the sector – we are informed after the launch of the Epilepsy Report 2019. Africa looks forward ahead to use the report to ensure inclusion of persons with epilepsy in reducing the burden, fighting stigma, reducing the treatment gap and prevention of epilepsy. There is a high need to ensure that as a region we have a coordinated action to prioritize epilepsy.

As we move forward as a region, we will need to refocus our attention to the needs of persons in the continent and mainly our Chapters in terms of capacity building, resource mobilization, not leaving our youths and women with epilepsy behind. However, change as we know takes time, effort and persistence. I would, therefore, like to acknowledge all those advocates for change that make the IBE family tick at all levels. We should all look forward to playing our part in this process

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



Launching Edycs

Epilepsy School Network EPILEPSY & SEIZURE DISORDER MANAGEMENT WORKSHOP

**Thursday 13 June 2019 – MACOSS Regional
Leadership Center,
Reduit, Mauritius**

Workshop Report

Background

More than 50 million people are living with epilepsy globally and the prevalence of epilepsy in Mauritius is estimated at **1% according to the WHO**. Epilepsy is one of the most common pediatric neurological disorders with higher incidence during the school years that causes recurring seizures in children and it can be the result of a condition such as cerebral palsy or strokes, but there is often no known cause. Edycs Epilepsy Group works with a wide spectrum of institutions including schools. Fewer pupils diagnosed with epilepsy and associated disorders were referred to Edycs Epilepsy Health Service Center for support and rehabilitation. It is on this very basis that Edycs Epilepsy Group came forward with this network in view of capacitating school teaching and non-teaching personnel in addressing the academic needs of children with epilepsy in the Republic of Mauritius.

The workshop

The launching of Edycs Epilepsy School Network witnesses the participation of 34 school personnel from various different educational institutions. The registration started at 09:00 and Nabeel Heeraman, Project Officer Edycs Epilepsy Group was the moderator for the workshop. Mr. Youssef Noormamode,

President Edycs Epilepsy Group was the first to address the audience laying emphasis on the school involvement in the upbringing of a child and to have a better understanding of their attitudes and behaviours most particularly those with epilepsy. He also outlined the support and contribution of educational institutions, where workshops and seminars shall be the key elements in enhancing the skills and responsiveness of teachers when facing with someone having epilepsy in the school setting. On the second note, Mr. Paramasiva Chengan stipulated that this network shall be a sustainable one, where long term relationships established with schools will undeniably raise epilepsy awareness among school personnel and also among students. The first session ended with the presentation of Membership Certificates awarded to the institutions.

At 10:30, Jawad Levraut, a French intern gave a presentation on the workshop objectives, followed by the presentation of Mr. Youssef Noormamode on the profile of Edycs Epilepsy Group and Nabeel Heeraman came forward with the objectives of the Edycs Epilepsy School Network. Dr. Umar Jomeer, General Practitioner and Yasheer Soohun, Occupational Therapist highlighted on the topic 'Understanding Epilepsy and Seizure Disorder Management' with video also being projected. Yasheer Soohun also gave an insight on the impact of epilepsy in the classroom and the psychosocial effects of epilepsy. Mr. Paramasiva Chengan came forward with the Promotion of Disability Human Rights – Inclusive Education, highlighting the

Conventions pertaining to Inclusive Education. At 13:00, we had a networking lunch and a practical demo was being enacted with Dr. Umar Jomeer as resource person and the help of one participant was sought.

Then a small exercise was held where the participants were asked to split in 4 groups and they had to work on the two following questions:

- 1. What Teachers can do to support Pupils with Epilepsy?**
- 2. How Teaching and Non-Teaching Staff including students can help raising epilepsy awareness?**

After nearly one hour, each group designated one group rapporteur to come forward and present their findings to the audience. Then Mr. Youssef Noormamode stated that after this one whole day workshop, each participant shall be acting as Epilepsy Ambassador within their school setting and their institutions be the force to lobby and advocate for the Rights of Children with Epilepsy. The workshop ended at 16:00, with the presentation of Attendance Certificates to all the participants and a thanking note from the President Edycs Epilepsy Group stating the importance of the institutions in fighting for the Rights of Persons with Epilepsy in the Republic of Mauritius.



New Feature

Article of Interest by Marina Clarke:

Liberia: Child Battles Spell for Decades

By Magdalene Saah

At the age of four months, Paul Neah had seizure one day when he was left at home with his siblings in a suburb of Monrovia. After he was taken to a hospital, doctors believed that Paul's illness was caused by high fever. Since then, Paul has struggled with frequent seizures. His impoverished parents would usually help him with some medications, but every now and then devastating seizures would strike. The despair of his parents escalated as the seizures took a toll on their 12-year-old son. They have visited several hospitals to get the help their son requires, but none has proved successful.

According to the World Health Organization, 1 in 4 people will experience mental health problems at some stage in their life. And service delivery reports from Mental Health Clinicians trained by the Carter Center show that seizure related cases constitute a significant proportion of conditions seen by the clinicians. Mental Health Clinicians trained by the Carter Center show that seizure related cases constitute a significant proportion of conditions seen by the clinicians. Around 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally. Nearly 80 percent of people with epilepsy live in low- and middle-income countries with Liberia being no exception. It is estimated that up to 70 percent of people living with epilepsy could live seizure free if properly diagnosed and treated. Neurological disorders in children occur when something is abnormal in the brain, the nervous system or the muscle cells. These disorders can vary from epilepsy to migraine headaches to tic or movement disorders and more. Children are either born with the neurological disorder like having fluid in the brain or they acquire the disorder later in life as a result of a traumatic injury or serious infection.....

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Promotion of Disability Employment Rights in Persons with Epilepsy (PWE)

Wednesday 10 April 2019

**Venue: 1st Floor Conference Room, Le Saint
Georges**

**Hotel, Port Louis, Mauritius
WORKSHOP REPORT**

Edycs Epilepsy Group (Mauritius) with support from the National CSR Foundation, the Ministry of Industrial Relations & Employment and the Africa Disability Alliance organized a workshop in epilepsy and employment issues. The workshop was held on Wednesday 10 April 2019 at the Conference Room of le St Georges Hotel, Port Louis Mauritius attended by 50 representatives from the Corporate Institutions, the Ministries, Human Rights Commission, Civil Society Organisations, Persons with Epilepsy and their families.

The association of epilepsy and employment is poorly understood. The purpose of this report is to summarize the presentations and discussions of the workshop.

The Official Opening ceremony was attended by the following key stakeholders:

- His Excellency, Mr. YKJ Bernard Yeung Sik Yuen, Commissioner of African Commission on Human & People's Rights
- Mr. Medavy Pillay Munien, Chairman of the National CSR Foundation
- Mr. Vivek Doobree, Senior Labour and Industrial Relations Officer, Ministry of Labour, Industrial Relations, Training and Employment

Mr. George Ibrahim from SMCOA

The ceremony comprising of speeches was followed with the presentation of T-Shirt on the Promotion of the Rights of Persons with Epilepsy.

PURPOSE OF THE REPORT

The purpose of the report is to provide an insight on the presentations and discussions on the issues of epilepsy and employment in relation to the

UNCRPD, the African Charter on Human Rights of Persons with Disabilities also referred to the Africa Disability Protocol and the Training and Employment of Disabled Persons Act.

It further provides for an opportunity to develop a strategic developmental perspective in creating a conducive environment where Persons with Epilepsy can enjoy their Rights, just like any other citizen in getting access to employment.

RATIONALE OF THE WORKSHOP

Epilepsy is the most common serious brain disorder and a global problem affecting all ages, religions and social background. It imposes enormous physical, psychological, social and economic burden on individuals and families, especially due to misunderstanding, fear and stigmas. According to the WHO Report 2001 estimates about 50 million people affected by epilepsy, 10 million in Africa while 1% of the total burden of disease in the world result from it. This calculation of the burden of the disorder takes into account premature deaths resulting from the disorder as well as the loss of healthy life years due to disability. In Mauritius, the prevalence of epilepsy is estimated at 1% of the population including Rodrigues Island, the 10th district of the Republic of Mauritius.

Persons with epilepsy are confronted with numerous challenges among others:

- Psychosocial difficulties which have a huge impact on their quality of lives (QOL)
- Understanding medical language and epilepsy information
- Employment and driving
- Stigmas
- Physical and sexual abuse
- Marriage

Employment is one of the biggest challenge facing People with Epilepsy in Mauritius. Approximately 50% of Persons with Epilepsy have difficulty finding and keeping a job. Of those who do not find employment due to the severity, frequency of seizures, medication side effects and associated comorbidities such as depression, anxiety disorder and migraine live on

a social aid allocated by the Disability Unit of the Ministry of Social Security.

Official Opening Ceremony

The Official Opening Ceremony started at 09h45. Nabeel Heeraman was appointed Programme Moderator, who made a welcoming speech thanking Chief Guests: His Excellency Commissioner YKJ Bernard Yeung Sik Yuen, Mr. Medavy Munien Pillay, Mr. Vivek Doobree, Mr. George Ibrahim, President of Edycs and Board Members, Representatives of Corporate Institutions, Representatives of Press and Media, Persons living with Epilepsy and families and Member of the audience for responding positively to the invitation of Edycs Epilepsy Group.

This was followed by the speech of Mr. Youssouf Noormamode, who clearly pointed out that Persons living with Epilepsy shall not be discriminated on any ground when looking for a job or to remain in a specific job if seizures occurred. He further added that they should not



be marginalized on this very basis. His Excellency Commissioner YKJ Bernard Yeung Sik Yuen from the African Commission on Human and People's Rights shared with the audience his experiences while being a commissioner in that high level institution but also broadened our knowledge on the road leading to the Ratification of the Protocol (ADP) designed by the Africans for the Africans. Mr. Medavy Munien Pillay, Chairman of the National CSR Foundation expressed his continuous support to organizations like Edycs Epilepsy Group in its furtherance to address societal problems such as epilepsy in the Republic of Mauritius. The Chief Guests came forward for the presentation of the Promotion of Human Rights T-Shirts with support funding from the NCSR Foundation.



Summary on the Discussions and Presentations

Presentation 1 – Saint Mark Coptic Orthodox Association (SMCOA), Mrs. Sarah Habib



The Saint Mark Coptic Orthodox Association (SMCOA) is an organization based in Egypt with which Edycs Epilepsy Group is in the process of signing a memorandum of collaboration and understanding in the medical field. The organization is represented by George Ibrahim, Sarah Habib and Youstina Mansy. The presentation of the organization was done by Sarah Habib, who gave an overview of the organization, the year it was founded and its milestone. The latter also pointed out that the SMCOA is present in several countries seeking collaboration with organization in the various field: education, poverty alleviation, empowerment & training, assisting organizations in providing medical support, providing technical expertise and also in the up-skilling of staff of those organizations.

Presentation 2 – Video Temoignage of Persons with Epilepsy

The video highlighted the stigmas faced by two Persons with Epilepsy, testifying how struggle it was for finding a job, to retain a job and most difficult to remain in a specific job though they are qualified for that specific job position. This also depicted how marginalized they are in the

employment sphere within the society just because they suffer from a specific form of disability. Indeed this workshop sent a message to all corporate institutions, underlining the pragmatic element of how employing someone with epilepsy can be prove beneficial for the organization as studies have shown that they even perform much better than others without disabilities, thus highlighting their effectiveness in their performances.

Presentation 3 – Living with Epilepsy and Employment Issues, Mr. Ashvin Dana Candassamy



Ashvin Dana Candassamy delivered a really moving testimony to the audience, where he related all the difficulties he faced to find jobs and the circumstances leading to his firing

despite the fact of his positive performance. He also pointed out how his different employers looked for excuses just not to retain him due to his epilepsy, where he just have to continuously seek jobs.

Presentation 4 – Epilepsy and Employment, Mr. Yasheer Soohun



Yasheer Soohun, Occupational Therapist in his presentation made a thorough insight of how Persons with Epilepsy are viewed

from the mainstream society, whereby just disclosing one's epilepsy during the interview can lead to the disqualification of the candidate on this very basis. He also elaborated on the issue of why employing someone with epilepsy and the jobs that one with epilepsy can or cannot perform.

Presentation 5 - UNCRPD/African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (ADP)/TEDPA, Mr. Paramasiva Chengan

Paramasiva Chengan, Deputy President Edycs Epilepsy Group outlined the different instruments aiming to protect the Rights of Persons with Disabilities:



UNCRPD, Article 27 – Work and Employment

“States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.”

African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (ADP), Article 15 – Right to Work

“Every person with a disability has the right to decent and productive work, to just and favourable conditions of work, to protection against unemployment, to protection against exploitation and to protection from forced or compulsory labour.”

“Prohibiting discrimination on the basis of disability with regard to all matters concerning all forms of employment, including employment opportunities, vocational training, conditions of recruitment, hiring and employment, continuance of employment, career advancement, and safe and healthy working conditions.” “Protecting the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work and the right by persons with disabilities to exercise their labour and trade union rights.”

“Employing persons with disabilities in the public sector, including by reserving and enforcing minimum job-quotas for employees with disabilities.”

“Promoting the employment of persons with disabilities in the private sector through appropriate policies and measures, including through the use of specific measures such as tax incentives.”

“Ensuring the reasonable accommodation is provided to persons with disabilities in the workplace.”

“Ensuring that employees with disabilities or those who become disabled are not dismissed from their jobs on the basis of their disability.”

- Continental Plan of Action – African Decade for Persons with Disabilities (2010-2019) African Union Disability Strategic Policy Framework
- Strategic Area 2: Reducing Poverty & Enhancing Economic Empowerment n Training and Employment of Disabled Persons ACT (TEDPA), Paragraph 14. Duty to provide suitable employment

“No disabled person shall be employed to perform work which, having regard to the nature of his disability is not suitable.”

Presentation 6 – Employment Rights Act, Mr. Vivek Doobree

Vivek Doobree, Senior Labour & Industrial Relations Officer gave an insight on the Act that governs employees’ rights in the Republic of Mauritius where we cannot gainsay the fact that Persons with Disabilities can also avail this prominent instrument for the protection of their Rights in regards to employment.

Presentation 7 – Access to Employment & Disability Rights, Mr. Coomara Pyaneandee

Barrister-At-Law, Vice Chairman UNCRPD and a United Nations Expert, Coomara Pyaneandee opined the very fact that Persons with Disabilities need to enjoy all their Rights, where he himself is an



example. Living himself with a disability has at any point in time hamper or be regarded as a burden in the furtherance of his ambition and zeal to practice as a lawyer, while being an expert in the field of disability. His eminent book entitled,

‘International Disability Law’, to which he made some references, encloses all the very aspect of disability that one can probe into to strengthen his knowledge about the different jurisdiction that exists governing the Rights of Persons with Disabilities.

The International Disability law books were distributed to the Chief Guests including representatives of the SMCOA and the SBM Foundation.



Please contribute to the newsletter:

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: 4th African Epilepsy Congress – Entebbe, Uganda