



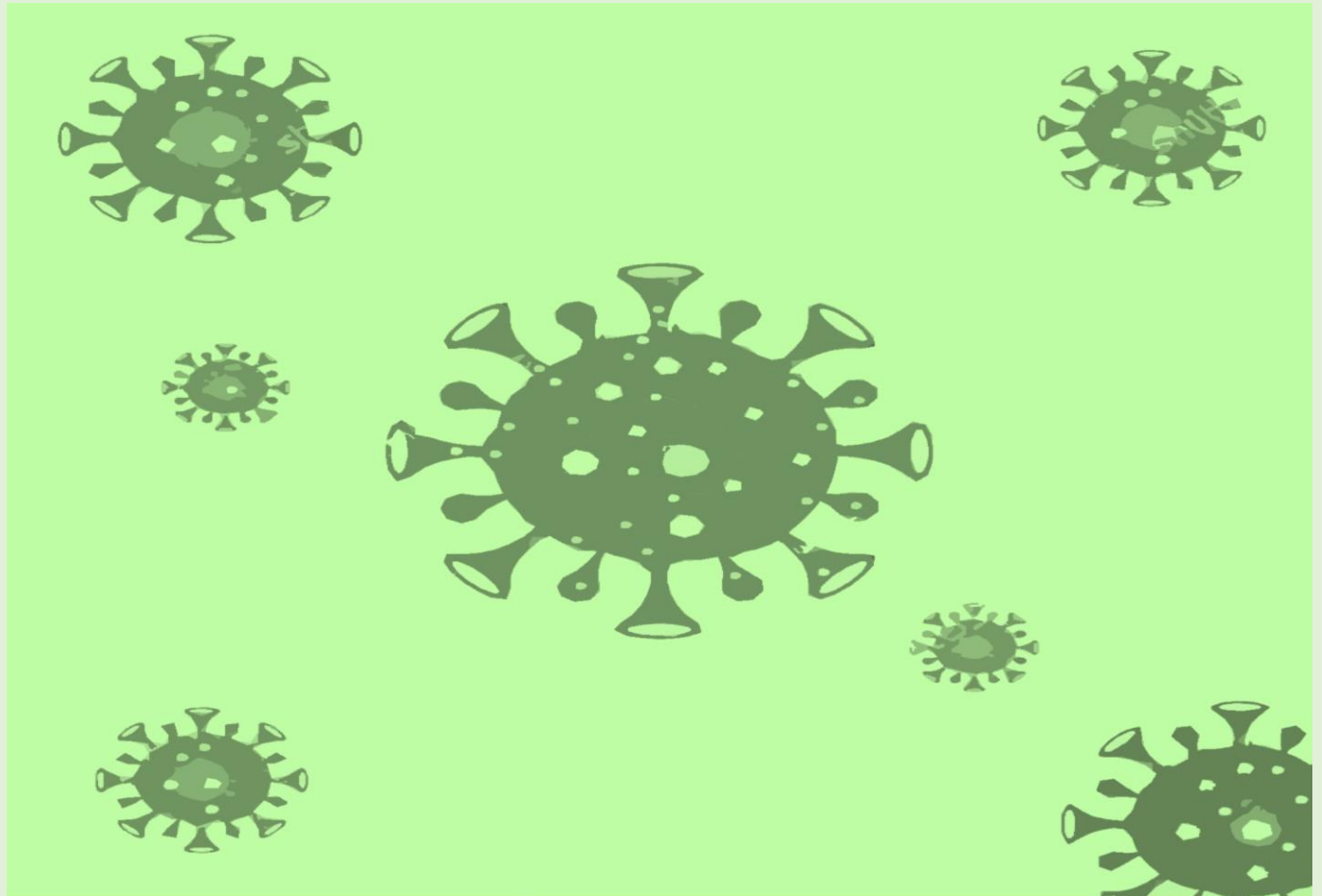
# EPILEPSY AFRICA NEWS

Issue 23

MARCH/APRIL 2020

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

**COVID SPECIAL**



## Contents

- **Epilepsy and COVID-19**

**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** [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com) or [amos.action@yahoo.co.uk](mailto:amos.action@yahoo.co.uk) Enjoy 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](https://twitter.com/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 [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com). You can also catch up on missed issues on <https://www.ibe-epilepsy.org/publication`s/regional-news/> and [www.epilepsyafrika.org](http://www.epilepsyafrika.org)

## CHAIRPERSON/EDITOR'S MESSAGE

**Dear Reader,**

A gloomy state of affairs emerged during the period with the advent of the Corona Virus in our Region. The world was affected in all aspects of life, business coming to a near standstill and virtual communication realized. The situation has affected the flow of information as little or no activity is being done. This article therefore will highlight messages on the **COVID-19** other than what was announced in the last issue of the Newsletter. Aware of the effects of anxiety on our members a special letter has been written by AREC for you;



### **Distinguished Chapters and Friends of Africa Regional Epilepsy Committee (AREC),**

I hope you are all doing well. More importantly, I pray that you are all safe during this challenging time, as the whole world is experiencing the Corona-virus. On behalf of the AREC and International Bureau of Epilepsy family, I would like to express our sincere solidarity with you all and your families wherever you are.

At this time, we share our utmost concern towards the safety and well-being of our sisters and brothers, especially our children and seniors with epilepsy. We recognize that this pandemic is doubly challenging for us with epilepsy, realizing that many of us may find it difficult to shelter ourselves from the terrible danger that this worrisome and critical disease may cause us and our families. Furthermore, we regretfully recognize that the majority of persons with epilepsy in the global south may not have access to sufficient health care or adequate community support. Unfortunately, health care programs around the world, mainly in the global south, continue to show their perpetual denial towards persons with epilepsy. Particularly, children, women, and elderly people with epilepsy continue to be left behind. Many countries in the global south continue to lack all means of accessible medical information and inclusive health care programs, the matter which would increase chances of keeping our colleagues with epilepsy to be subject to the disastrous implications of this dangerous pandemic.

AREC would like to urge its country representatives to do all that they can to:

- Ensure that their constituencies are adequately prepared for remaining safe before such challenges caused by this global crisis.
- Follow up on any incident of exclusion that colleagues with epilepsy may encounter in case they need immediate medical support.
- Monitor the status of hospitals and medical centres to insure its accessibility and inclusivity of persons with epilepsy.
- Reach out to all stakeholders i.e. policy makers and government officials who are in charge of setting up emergency programs to insure that they are taking into account the criteria of inclusion and accessibility for persons with epilepsy.

- Work closely and coordinate with civil society to insure that persons with epilepsy are being included in their contingent emergency programs.
- Last but not least, maintain the closest communication possible with their constituencies and offer the maximum psychological support possible, so they can keep up with the isolation and home confinement that COVID-19 has imposed on all of us.

From the AREC leadership, we are committed to:

- a) Share with you all, whatever helpful information and guiding tools to help you remain strong and face this pandemic.
- b) Be your voice before all international entities that are trying to set up strategies for combating this disease.
- c) Intervene with all relevant stakeholders as much as possible, on your behalf and per your request, to help and support you during this time.
- d) Coordinate with other organizations, ensuring that whatever the international community is striving to do to fight this pandemic should be inclusive for our disabled sisters and brothers everywhere, and particularly in the global south.

Again, I share with you our organization's utmost solidarity, praying that you and your loved ones remain safe and sound, so we could all-together overcome this pandemic period in the life of our world. Keeping up the high morale is what we all really need in these extremely difficult days!

**Action Amos**  
**IBE Africa Vice President**

*If you have a story you'd like us to consider for publication, please contact:*  
[ibeafrica@gmail.com](mailto:ibeafrica@gmail.com), [amos\\_action@yahoo.co.uk](mailto:amos_action@yahoo.co.uk)

# RECOMMENDATIONS AND ADVICE FOR THE PUBLIC ON COVID 19

by World Health Organization

If you are not in an area where COVID-19 is spreading or have not travelled from an area where COVID-19 is spreading or have not been in contact with an infected patient, your risk of infection is low.

It is understandable that you may feel anxious about the outbreak. Get the facts from reliable sources to help you accurately determine your risks so that you can take reasonable precautions (*see Frequently Asked Questions [www.who.int/news.room](http://www.who.int/news.room)*).





Seek guidance from WHO, your healthcare provider, your national public health authority or your employer for accurate information on COVID-19 and whether COVID-19 is circulating where you live. It is important to be informed of the situation and take appropriate measures to protect yourself and your family (*see Protection measures for everyone*).

If you are in an area where there are cases of COVID-19 you need to take the risk of infection seriously. Follow the advice of WHO and guidance issued by national and local health authorities. For most people, COVID-19 infection will cause mild illness however, it can make some people very ill and, in some people, it can be fatal. Older people, and those with pre-existing medical

conditions (such as cardiovascular disease, chronic respiratory disease or diabetes) are at risk for severe disease (*See Protection measures for persons who are in or have recently visited (past 14 days) areas where COVID-19 is spreading*).

[https://www.who.int/docs/default-source/coronaviruse/covid-strategy-update-14april2020.pdf?sfvrsn=29da3ba0\\_19](https://www.who.int/docs/default-source/coronaviruse/covid-strategy-update-14april2020.pdf?sfvrsn=29da3ba0_19)

Be **SMART** & inform yourself about #coronavirus

-  Follow accurate public health advice from WHO & your local health authority
-  Follow the news on latest coronavirus updates
-  To avoid spreading rumors, always check the source you are getting information from
-  Don't spread rumors

Learn more to Be **READY** for #COVID19:  
[www.who.int/COVID-19](http://www.who.int/COVID-19)

## Article of Interest

# #PurpleDay: Epilepsy safety tips on COVID-19

By [Fredrick Beuchi Mboya](#), Kenya  
26th Mar 2020



***Having epilepsy does not increase the risk of getting Covid-19*** (Shutterstock)

Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26th annually, people in countries around the world are invited to wear purple and host events in support of epilepsy awareness.

### **Epilepsy Safety tips on COVID-19**

If you have epilepsy or look after someone with epilepsy, you may be concerned about what the recent coronavirus outbreak means for you.

**According to Center for Disease Control and Prevention (CDC), having epilepsy does not increase the risk of getting Covid-19 and does not increase the severity of Covid-19.** The risk of Corona Virus is increased in persons with weakened immune systems, older people, and those with long-term conditions like diabetes, cancer and chronic lung disease.



***It is important to keep taking your epilepsy medicine***

It is important that those living with Epilepsy condition identify triggers for their seizures.

Once the trigger is clearly identified, this helps to manage the seizure occurrences. Feeling unwell generally and a rising temperature can be a trigger for seizures. Coughing may keep you up at night, and a lack of sleep can be a trigger for seizures too. If you show symptoms such as a high fever, cough, or difficulty breathing you might be at risk of increased seizures. COVID-19 signs and symptoms are characterized by fever, cough and shortness of breath.

There is no reported evidence of increased risk of coronavirus infection in people taking antiepileptic medications. Therefore, it is important to keep taking your epilepsy medicine as usual throughout any illness.

It is recommended that everyone takes stringent measures to follow the Government guidelines on social distancing, self-isolation and maintaining good hygiene practices.

### ***Lighting Nairobi's skyline purple***

For this year's Purple Day, the message remains to encourage all persons living with Epilepsy condition in Kenya to seek medical treatment as Epilepsy is manageable! Under the NECC umbrella, the UAP tower will be lit in purple from 8pm tonight (26th March) to stand in solidarity with all persons living with Epilepsy.

*- The writer is the National Epilepsy Coordination Committee (NECC) National Secretary (Kenya), and an Epilepsy Awareness ambassador*

<https://www.standardmedia.co.ke/evewoman/article/2001365760/purpleday-epilepsy-safety-tips-on-covid-19>

## KEY COVID RESOURCE

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- [“Disabled People Are Not Simply Dispensable During a Pandemic”](#) Article by Liz Moore on Rooted in Rights discussing the experiences of persons with disabilities during COVID-19
- [“Protect Rights of People with Disabilities During COVID-19”](#) Article by Human Rights Watch on ensuring access to information
- [“The Coronavirus Pandemic Is Settling Some Old Arguments About Ableism”](#) Commentary by Andrew Pulrang for *Forbes*

### OPEN LETTERS

- [“COVID-19: Who is protecting people with disabilities?”](#) A message from Ms. Catalina Devandas, the United Nations Special Rapporteur on the Rights of Persons with Disabilities and former staff member of DRF, urging protection for persons with disabilities
- [The Global Action on Disabilities has issued a joint statement](#) outlining what a response that is inclusive of persons with disabilities should look like. Available in [Word](#) and [PDF](#)
- [UN Secretary General message about importance of a disability-inclusive response to COVID-19](#)
- [AskWHO](#) Video on the World Health Organization addressing questions on disability considerations during #COVID19 (note: captioning not available)
- [Open Letter](#) to the UN Secretary General from the Thematic Group on Disaster Risk Reduction calling for the inclusion of persons with disabilities during #COVID19 responses
- [Joint statement](#) from the Chair of the CRPD Committee and the Special Envoy of the United Nations Secretary-General on Disability & Accessibility on ensuring safety and security of persons with disabilities during #COVID19

### 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
3. Questions on epilepsy care
4. Photographs

**Did you enjoy reading our newsletter?** Please give us some feedback: **Email -[ibeafrica@gmail.com](mailto:ibeafrica@gmail.com)**  
**OR [amos\\_action@yahoo.co.uk](mailto:amos_action@yahoo.co.uk)**

**If you have any other topics to suggest, please email us at [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com) by 20<sup>th</sup> of each month**

### Next Issue to feature:

- **Quarterly Africa Regional Meeting Report**
- **Reports from Mauritius, Sierra Leone, DRC, Rwanda and Malawi**
- **Making Epilepsy a A Health Priority Project**