World Health Organization

Seventy-second World Health Assembly / Soixante douzième Assemblée mondiale de la Santé
Palais des Nations
May 2019 / Mai 2019

Side event application / Formulaire de demande de réunion parallèle

Contact

Name/Nom: Dr. Aleksey Novozhilov	Date of application/Date de la demande: 27/03/2019
Delegation(s)/Délégation(s): Russian Federation	
Telephone, Email/Téléphone, courriel: +41766408703	

Concept

Description of proposed side event, including objective, expected results, proposed programme and speakers* /
Description de la réunion parallèle proposée, y compris les objectifs, les résultats attendus, l'ordre du jour et les orateurs* :

Background

Epilepsy affects over 50 million people worldwide. Among neurological diseases, it accounts for the highest disability life year rates. In terms of of disability weight, severe epilepsy ranks fourth among 220 health states surveyed by the Global Burden of Disease study.

Epilepsy also carries a high risk of premature mortality, due to seizure-related accidents and the occurrence of sudden unexpected death, which alone is the second leading neurologic cause of total lost potential life-years after stroke.

Persons with epilepsy are stigmatized in all societies, with the consequences of prejudice and discrimination adding to the medical burden of the disease. Epilepsy affects people of all ages, gender, race and income levels, but poor populations and those living in vulnerable situations, in particular in low-and middle-income countries bear a disproportionate burden, posing a threat to public health and economic and social development.

Epilepsy belongs to the non-communicable diseases (NCD); furthermore, it is often comorbid to a number of other somatic and psychiatric conditions; a bidirectional association has been established between epilepsy and depression, cerebrovascular disease, stroke and dementia.

Health care for persons with epilepsy involves providing medical and social services to decrease morbidity, mortality, and to improve psychosocial outcomes. Given the size of the burden of epilepsy, the challenges facing governments to provide universal health coverage (UHC) are substantial. Access to care for persons with epilepsy varies considerably across and within countries, with unmet needs being particularly high in LMICs.

Epilepsy is the only severe and disabling neurological disease that is fully treatable in the majority of cases. About two thirds of persons with epilepsy achieve complete seizure control if treated with available medications, and can live a normal and fully productive life. Yet, access to anti-seizure medications remains out of reach for the majority of persons with epilepsy, particularly in low and middle income countries, where the most persons with epilepsy live; the treatment gap there is over 75%. Notably, most medicines for epilepsy are inexpensive, with the cost of one year of treatment with phenobarbital being as low as 3 USD.

In May 2015, Member States unanimously supported WHA68.20, the 'Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications'. The resolution called for collective action to improve awareness, fight prejudice and discrimination, and address the treatment gap.
In 2019 the Global Epilepsy report was prepared in collaboration between the WHO, ILAE and IBE. The Global Epilepsy Report raises epilepsy as a public health priority in order to address these gaps through a cost-effective, coordinated response. People with epilepsy and their families are asking that this unique opportunity not be lost, and that global action be taken.
The 144 WHO Executive Board meeting included the item on epilepsy with the focus on the Global Action Plan on epilepsy in the Agenda of the 146 WHO EB meeting.

Proposed Side Event
This side event will bring together policy makers, NGOs, patient's, health care leaders and Member States to develop next steps for implementation of WHA68.20, Ministries of Health from different WHO regions will identify the underlying systemic issues that affect access to universal health care (UHC) and essential medicines for persons with epilepsy in their regions. The Global Epilepsy report will be presented and the key directions of the Epilepsy Action Plan will be identified. The speakers will address the barriers and recommend solutions to strengthen systems and practices, and issue a call for urgent action by all key stakeholders at the national and international levels.

The objectives of this side event are to:

- To review the scope and magnitude of the burden of epilepsy globally and to identify the underlying systemic issues affecting access to UHC and essential medicines.
- To pre-launch the Global Epilepsy report and to discuss the key strategies for strengthening leadership and governance in epilepsy, facilitating the comprehensive health care response, eradication of stigma, extending the prevention and research in epilepsy.
- To learn from the experiences of several Member States who have implemented demonstration projects to improve epilepsy care and access to anti-seizure medicines.
- To strengthen Member State commitment to develop a plan of action to address epilepsy as a public health priority.

Expected Results:
A scaling up of Member States' political commitment towards addressing the gaps in access to essential health-care services and essential medicines for epilepsy.
Identification of factors affecting access to essential medicines, where regulations represent a hurdle to their availability in many lower and middle income countries.
Development of partnerships and initiatives to address the major modifiable risk factors for epilepsy: perinatal injuries, central nervous system infections, traumatic brain injury and stroke.
Presentation of the Global Epilepsy Report and identification of the key directions of the Global Action Plan on epilepsy

Proposed Programme and Speakers:
The key points will be addressed in the presentations.

1. WHO leadership
2. ILAE and IBE executives
3. Russian Federation

4. Representatives of the co-sponsoring Member States
5. Representatives of the WFN and other co-sponsoring non-state actors
6. Patient representative

Alignment to WHO priorities:

SDG 3.4: "By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being."

SDG 3.8: "Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all."

Political declaration of the third high-level meeting of the UN General Assembly on the prevention and control of non-communicable diseases A/RES/73/2 18-16893 3/7 recognized that the mental disorders and neurological disorders contribute to the global burden of non-communicable diseases and that people living with these conditions face stigma and discrimination, being more susceptible to having their human rights violated and abused, and also have an increased risk of other non-communicable diseases and therefore higher rates of morbidity and mortality.

Event details / détails de la réunion

Date 21.05 or 22.05	Time/Heure Lunch time
Expected number of participants/Nombre de participants attendus : 150	
Exact title of the event/Titre exact de la réunion: Epilepsy: A Public Health Priority	

Interpretation/Interprétation

Interpretation may be provided in the official languages and the estimated costs are as follows: 2 languages: 2568 CHF; 3 languages: 5136 CHF; 6 languages: 11985 CHF.

L'interprétation peut être assurée dans les langues officielles aux coûts estimés suivants : 2 langues-2568 CHF; 3 langues : 5136 CHF; 6 langues : 11985 CHF.

Are interpretation services requested? / L'interprétation est-elle requise ?	Yes/Oui +	No/Non ☐			
(If yes, which languages)/(Si oui, en quelle langue)					
English/Anglais +	French/Français ☐	Russian/Russe +	Spanish/Espagnol ☐	Chinese/Chinois ☐	Arabic/Arabe ☐
Other language/autre langue:					

Invoice to be sent to/ Facture à envoyer à:

Name/Nom Donna Cunard, MBA, Financial Manager of the International League against epilpesy

Postal address/ Adresse postale

2221 Justin Rd, #119 - 352, Flower Mound, TX 75028

P: + 860.865.7547 Ext 2 | Fax: + 860.201.1111

E-mail/Courriel dcunard@ilae.org

Room Layout/Aménagement des salles

Due to type of furniture and technical equipment in the room, the layout of the rooms cannot be changed. For information regarding the location and layout of rooms at the Palais des Nations, please see:
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***Badges/ Badges d'accès**

WHA side events are for participants of the WHA and, as such, panelists and participants should be drawn from those participating in the Health Assembly.

Les réunions parallèles sont réservées aux participants de l'Assemblée; Les orateurs de ces réunions doivent donc être choisis parmi ceux-ci.

Please complete the form and send it to / Merci de remplir le formulaire et de l'envoyer à

hqgoverningbodies@who.int

by 29 March 2019