9 April 2021

Dear Dr Ren,

The International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), the World Federation of Neurology (WFN) and the International Childhood Neurology Association (ICNA) welcome the opportunity to provide joint comments on the Discussion Paper circulated by the WHO secretariat on 8 March 2021 that will inform the development of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders.

Together the ILAE, IBE, ICNA and WFN represent the vast majority of health care professionals working in the fields of epilepsy and all neurological subspecialities globally as well as the major patient organizations empowering and supporting people with epilepsy and other neurological disorders.

ILAE has over 26,000 professional members from 123 National Chapters and is responsible for publishing three preeminent journals – *Epilepsia, Epilepsia Open and Epileptic Disorders* – that provide leading edge research into epilepsy as well as guidelines and standards for clinical practice. ILAE supports specialized training in epilepsy through the ILAE Academy and dissemination of learning and best practice during biennial Regional and International Congresses.

IBE represents 50 million people with epilepsy, their care providers and care partners through a network of 140 chapters in over 100 countries. IBE supports advocacy at country and global level to further the rights and needs of those affected by epilepsy.

WFN represents all neurologists worldwide, is composed of 122 member societies and aims to foster brain health and quality neurological care globally. It employs educational activities and advocacy to further its aims, supporting training centres in francophone and anglophone Africa and travelling fellowships for young neurologists. The WFN also promotes awareness of specific neurological diseases through the annual World Brain Day programmes and the biennial World Congress of Neurology as well as brain health through the Brain Health Initiative and the Neurological Needs Registry developed from 117 member societies.

ICNA has over 3400 members from 123 countries who are all clinicians involved in the care of children with neurological disorders. The Association collaborates closely with all regional child neurology organizations ensuring that there are clear communications and understandings from an international through to local point of care delivery for children with neurological disorders.

All four organizations are in official relations with WHO and appreciate the work of the WHO secretariat in developing the Discussion Paper, and in engaging with health professionals and those with lived experiences as part of the consultation process to develop the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. However, we wish to raise a number of concerns based on our collective professional expertise and lived experience. Each organization will also be submitting more technical and detailed comments and suggestions on the Discussion Paper through the WHO consultation portal.

Our major concern is that there appears to be **significant discrepancies** between the intent of Resolution WHA73.10 and the structure and priorities presented in the Discussion Paper. The five major amendments suggested in this letter are intended to ensure that the final Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders will align with the intent and priorities of Resolution WHA73.10.

1. The opportunity to build on epilepsy as an entry point to address specific needs and also strengthen other neurological services has been somewhat missed in the Discussion Paper

WHO declared, in its landmark global report on epilepsy[1], that action to meet the needs of the 50 million people worldwide living with epilepsy should be considered a **'public health imperative'.** Resolution WHA73.10 clearly singles out epilepsy as a disorder with an unacceptably high health and social burden in need of specific attention. Throughout the Discussion Document however, epilepsy is either missing or at the periphery. This has created a **significant discrepancy** between the intent of the Resolution and the prioritization presented in the Discussion Paper.

Further, the Discussion Paper does not effectively build on the proposal in Resolution WHA73.10 to optimize the prevention, treatment and care synergies that exist between epilepsy and other neurological disorders. This again has created a **discrepancy** between the two documents. If not corrected, this could lead to a **significant missed opportunity** to strengthen services for both epilepsy services and other neurological disorders by building on these synergies and, where appropriate, utilizing **epilepsy as an effective entry point** to improve care and treatment for neurological disorders more broadly.

We would therefore propose that the document be reframed, and the Vision, Goal and Scope rewritten as follows:

VISION

The vision of the action plan is a world in which:

i. Brain health is valued, promoted, protected, and prioritized with strengthened governance for epilepsy and neurological disorders and with representation in national health policies, plans and budgets.

ii. Epilepsy and other neurological disorders are prevented and treated avoiding deaths and disability and improving Quality of Life through appropriate, affordable, and quality services, essential medicines and ongoing research.

iii. Social, economic, and educational needs, and freedom from discrimination for persons with epilepsy and other neurological disorders, are prioritized and protected in legislation; such protection extending also to families and caregivers.

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[1] Epilepsy: A public health imperative. Geneva: World Health Organization; 2019 https://www.ilae.org/about-ilae/policy-and-advocacy/international-public-policy-activities/global-epilepsy-report-2019.

GOAL

To reduce the stigma, impact and burden of epilepsy and other neurological disorders, including associated mortality and morbidity, by leveraging the prevention, treatment and care synergies between epilepsy and other neurological disorders as well as, where appropriate, utilizing epilepsy as an effective entry point for strengthening services and improving the health, social services, and quality of life of persons of all ages with all forms of neurological disorders.

SCOPE

The wording from Resolution WHA73.10 (pp2) should replace the wording in paragraph 13 of the Discussion Paper to ensure proper alignment with the intent of the Resolution. The scope should therefore be defined as: "neurological disorders are conditions of the central and peripheral nervous system that include epilepsy, headache disorders, neurodegenerative disorders, cerebrovascular diseases including stroke, neuroinfectious/neuro-immunological disorders, neurodevelopmental disorders and traumatic brain and spinal cord injuries."

2. Addressing stigma, exclusion, and discrimination requires more focus

People living with neurological disorders suffer from high rates of stigma, exclusion, and discrimination. People with epilepsy – and often also their families and communities – are the most stigmatized group in the world.

People living with epilepsy have consistently reported that exclusion, human rights violations, and lack of equal opportunities are the elements associate with their disorder that **most negatively impact** their health and well-being. Many of those with neurological disorders have similar experiences.

Although there is mention of these issues within the Discussion Paper, they are **not afforded the attention that is needed to address these critical issues.**

We believe that addressing stigma, exclusion and discrimination requires its **own, specific Objective** and set of specific actions for Member States, WHO Secretariat and International Partners.

The IGAP should therefore be structured around **five** rather than the current four Objectives and include the proposed wording and sections for the new Objective:

Add new Objective: To Address Stigma and Discrimination and Promote Inclusion and Equal Opportunities for People Living with Epilepsy and Other Neurological Disorders

- Addressing legislation and policy gaps (new section)
- Advocacy and addressing stigma (current section 1.1)
- Role of other sectors – particularly education and employment (new section)

3. Further attention is needed to address out-of-pocket expenditure and to reduce the treatment gap for epilepsy and other neurological disorders

While it is important to pay attention to the promotion of brain health and addressing avoidable risk factors, the discussion paper lacks the **required balance and specificity** to address the two leading priorities of people living with epilepsy and other neurological disorders namely:

- Reducing the often crippling and **catastrophic out of pocket expenditure** suffered by patients and their families
- **Closing the treatment gap** by ensuring access to essential diagnostics, medicines, and treatment and address the critical shortage of trained work force

The current Objective 1 should be reformulated to focus on national plans and financing with increased attention to **addressing the out-of-pocket expenditure** and achieving Universal Health Coverage.

The current Objective 2 should be enhanced to place a clear focus on reducing the **unacceptable, global treatment gap** particularly for disorders such as epilepsy where effective treatments are available at very low cost, but which are still **out of reach for over 70% of the affected population.**

Additionally, in light of the learnings from the current pandemic, we also suggest that an eighth principle be added to the **Guiding Principles**, namely:

> **(viii) Protect access to and delivery of services and care for epilepsy and other neurological disorders during emergencies and times of crisis.**

Based on this additional principle, suggested actions to improve continuity of services should also be included in the reformatted Objective 1 (Planning and Governance) as well as under the current Objective 2 (Services).

4. The Needs of Children are poorly addressed in the Discussion Paper

Throughout the document the focus appears to be the adult population with the **needs of children and adolescents and the challenges of transitioning into adulthood neglected or poorly understood.** Paragraph 6 provides a very tangible example of this: headache is listed - inaccurately - as the most important neurological disorder in childhood and thus ignoring the large numbers of children with epilepsy and also with other complex neurological needs. These, and other significant inaccuracies, **must be corrected.**

5. There is inadequate focus on the needs of people living in Low Resource Settings

The document also appears to have been written from a high resource setting perspective and based on demographic and epidemiological data predominately arising from high income countries. The **needs of the 80% of people with epilepsy and other neurological disorders living in lower and lower-middle income countries** where risk factors, disease prevalence and resources differs considerably from those in high resource settings and **are not well reflected** in the Discussion Paper.

To address these last two critical issues, we suggest that WHO urgently form **two expert resource groups** to include external expertise to review the entire document:

- Expert resource group with a focus on the epidemiology and needs of children, adolescents, and the challenges of transition to adulthood

- Expert resource group with a focus on understanding the epidemiology, needs and service provision in lower resource setting

These two expert resource groups should be maintained throughout the process of developing the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders and be available to review, from these two specific perspectives, the draft plan and indicators when these become available later in the year.

We appreciate the time and work involved in developing the Discussion Paper and the opportunity to comment. However, we are concerned that there are significant discrepancies between the intent of Resolution WHA73.10 and the framing and content of the Discussion Paper. We hope that the above-mentioned suggestions can be incorporated into the draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders so that these misalignments can be corrected, and the intent of Resolution WHA73.10 fulfilled for the benefit of all persons living with epilepsy and other neurological disorders globally.

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