

The need to launch Global Campaign Against Epilepsy in South East Asia

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Epilepsy is a common and chronic neurological disorder that has been known to mankind since its own existence. First described in the western literature by Hippocrates about 2000 years ago, epilepsy has been described as *Apasmara* in the ancient Indian literature around 500-1000 BC. Epilepsy known as *Apasmara* in Sri Lanka also is known as *Mirgi/Lata/Laran* in parts of northern India, *Khichuni* in Bangladesh, *Ayan* in Indonesia, and *Rake Lom Ba Mu* or *Roke Lom Chak* in Thailand. Although known as a disorder for centuries, epilepsy is still perceived negatively with a significant societal stigma and medical, social, financial and psychological burden.

Despite the tremendous advances that have taken place with regards to many aspects of epilepsy, it continues to be a socially labeled disease with a significant amount of stigma still attached to it both in the developed and developing societies. In most developing countries availability of appropriate epilepsy care is largely confined to a few big cities but majority of the population in these countries still continues to live in far-flung villages. The attitudes towards a disease like epilepsy have considerably changed in the developed countries mainly because of the education standard of the population and the availability of appropriate health care facilities within easy reach of the people in all the communities.

The changing attitudes towards epilepsy over the centuries now form an integral part of history and must be encouraged. Those who have epilepsy must also take it a part of their lives because having epilepsy doesn't make most such people different from others in any major way. It is only for that brief period when the actual seizure is there, a person may not be normal. Otherwise, a person having epilepsy looks, talks and acts in the same way as everyone else. It is however not an uncommon experience that other people believe and expect that having epilepsy makes one different. It is their mistake because given the chance, people with epilepsy can probably live, work and function in this world as well as anyone

else. A greater awareness about the disease in the society certainly plays an important role in changing the societal knowledge, attitudes and practice of this important neurological disorder.¹

The World Health Organization (WHO) estimates that about three-fourths of the 50 million persons with epilepsy globally, today live in the developing world. The exact number of people with epilepsy in the South-East Asian region (SEAR) is not known. As per some studies, between 50-80% of people with epilepsy in the SEAR countries either do not receive any treatment or never contact any health care institution and a significant percentage of those receiving treatment drop out, mainly due to economic considerations. The stigma attached to epilepsy in the SEAR is mainly secondary to the lack of knowledge, ignorance and myths and misconceptions about its causation. Educating the general public about various aspects of epilepsy is perhaps the most cost-effective way to reduce the societal burden due to this disorder.

The WHO, the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) have identified epilepsy as a major thrust area and launched a Global Campaign against Epilepsy (GCAE) in 1997. At the International level, WHO, ILAE and IBE are strengthening the Global Campaign with other partners, such as UNICEF, particularly as epilepsy is common in children.

In September 1997, the Pan-American Health Organization (PAHO), the Regional Office of WHO for the Americas, adopted a resolution urging its Members States to develop programs for the control of epilepsy. In response to this, the secretariat of PAHO developed a strategy for a regional initiative to control epilepsy. Also in 1998, a European Regional Meeting was held in Germany, within the framework of the Global Campaign, which issued a European Declaration on Epilepsy. Further similar regional Declarations were formally adopted and issued in May 2000 at Senegal, Dakar (African Declaration) and in September 2000 in Santiago, Chile (Latin

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American Declaration).

In view of the challenge epilepsy poses in the developing countries, the 3rd Congress of the Asian & Oceanian Epilepsy Organisation was held in New Delhi from November 11-13, 2000. A special meeting “Epilepsy: A Public Health Priority in Asian & Oceanian Regions” was organized on November 10, 2000 at New Delhi. The meeting was attended by about 55 professionals from health and social sciences sectors and representatives from many other organizations of the region. The countries represented were: India, Japan, China, Pakistan, Bangladesh, Nepal, Sri Lanka, the Philippines, Korea, Indonesia, New Zealand, the Netherlands, UK, USA, Senegal, and Chile. Various aspects of the draft of the Asian & Oceanian Declaration on Epilepsy were discussed in detail. After the meeting on November 10, a core-group finalized the draft of the Declaration. The Draft was formally unanimously approved during the Closing Ceremony of the Congress on November 13, 2000. The North-American Declaration on Epilepsy was subsequently formally adopted in December 2000. It is now important that all concerned should join together and work towards achieving the objectives of the various Regional Declarations on Epilepsy.

The need to launch the GCAE in the SEAR is more acute than any other region of the world. The launch of GCAE should have begun with the SEAR. Although late, it can still be done. There are costs for doing this but the cost of not doing may be higher.

REFERENCE

1. World Health Organization. Regional Health Forum - WHO South-East Asia Region. The Asian-Oceanian Declaration on Epilepsy. WHO 2001; 5 (2):75-8.