

## PRACTICE OF NEUROLOGY

# Lao Association for Patient with Epilepsy: Report of activity 2011-2014

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### Abstract

In Lao PDR, the care of patients with epilepsy faces many challenges. There are around 50,000 people living with epilepsy (PWE) but only 10% have access to antiepileptic medication. The mortality is high among untreated PWE. Misconception about the disease and stigma are common in the general population. The availability of antiepileptic medication is poor. Knowledge on epilepsy among health personnel is poor. Improvement in the management of epilepsy in Lao PDR requires training of health workers on epilepsy, a system to provide antiepileptic drugs and improvement of knowledge on the causes and effective treatment of epilepsy among PWE and the public. The Lao Association for Patients with Epilepsy (APE) was established in 2011 with four main activities: organizing scientific conferences on epilepsy in Laos; providing three days training on epilepsy to health personal at both provincial and district levels; supporting the provision of antiepileptic drugs through a revolving drug fund at provincial and district hospitals; and promoting the dissemination of information on epilepsy to the public. Up to now, 31 health professionals among 52 who were trained on epilepsy provide consultations at both provincial and the district levels. A total of 129,200 tablets of a first line antiepileptic drug (phenobarbital) have been provided to provincial and district hospitals. An estimated 1,112 PWE are currently under treatment. There is a daily information campaign through the media; pamphlets and posters are disseminated at epilepsy clinics. A Lao medical network has been established that will improve access to treatment by PWE.

### INTRODUCTION

Epilepsy is one of the most common neurological disorders. It affects 70 million people worldwide; 80% of them live in developing country.<sup>1</sup>

The Lao People's Democratic Republic (Lao PDR) is a landlocked country (population 6.1 million), surrounded by China, Myanmar, Thailand, Vietnam and Cambodia.<sup>2</sup> In this country, epilepsy is a neglected disease, although it could easily become a controlled disease if a patient receive the appropriate medicine. Managing epilepsy faces several challenges in Laos. For example, it is estimated that there are around 50,000 people living with epilepsy (PWE) but only 10% have access to antiepileptic drug (AED) treatment.<sup>3</sup> The mortality is high among PWE

who do not receive the appropriate treatment.<sup>4</sup> Misconception about the disease, false beliefs and stigmatization are common.<sup>5</sup> Availability of AEDs is limited and knowledge of health workers about epilepsy is poor.<sup>6-8</sup>

In Laos, the management of epilepsy requires training of health workers on epilepsy, facilities for providing treatment (in terms of finance, geographic accessibility and drug procurement), a coalition of stakeholders and education programs for PWE and the population on the causes and treatment of epilepsy.

In 2009, the Francophone Institute for Tropical Medicine (IFMT) decided to complement its research activities with an intervention named "Initiative access to treatment for people with

epilepsy in Lao PDR". The main activities of the initiative consist of advocacy, training of health personnel, providing special consultations for PWE, writing guidelines for epilepsy management in Lao and ensuring availability of AEDs. The initiative includes an evaluation of these activities.

In order to contribute to efforts to reduce the stigmatization of PWE caused by socio-cultural beliefs about epilepsy and to promote access to treatment, a Lao Association for PWE (Lao APE) was established in 2011. Lao APE has 52 members in nine provinces: Vientiane (the capital city of Lao PDR), Vientiane province, Xaisomboun, Luangnamtha, Luangprabang, Xiengkhuang, Savannakhet, Champasak and Sekong. Most members are health workers, who were trained by the "Initiative access to treatment for people with epilepsy in Lao PDR" project.

The objective of this paper is to describe the activities performed by the Lao APE from 2011 to 2014.

### SCIENTIFIC CONFERENCE ON EPILEPSY

In collaboration with the "Initiative access to treatment for people with epilepsy in Lao PDR" project team at IFMT and the Integrated Epilepsy Research Group at Khonkean University in Thailand, two scientific conferences were organized on the 5<sup>th</sup> of December 2011 and the 31<sup>st</sup> of January 2013. These conferences aimed to increase public awareness of the burden of epilepsy but also to mobilize APE members. They provided an opportunity for sharing experience between different organizations, including the Ministry of Health, non-government organizations, international experts on epilepsy and health workers at the provincial level.

### TRAINING ON EPILEPSY FOR HEALTH WORKERS IN PROVINCES

Lao APE provided training on epilepsy to health personnel at three levels: provincial hospitals, district hospitals and primary health care in three provinces. In total, 52 health workers were trained. Training consists of a one-day theoretical course, one day of practical training on medical management and one day of case discussion.

To promote consultation on epilepsy, especially in remote areas, Lao APE provided support to a physician from a provincial hospital level for a three month period of training on epilepsy at Khonkean University, Thailand.

In total, 31 of the 52 health professionals who received training have provided consultations to PWE.

### ANTIEPILEPTIC DRUG SUPPLY AND NUMBER OF PWE TREATED BY TRAINED HEALTH PERSONEL

One of challenges faced by doctors in Laos is the low availability of AEDs. One of Lao APE's main activities is the supply of AEDs to a revolving drug fund for referral, provincial and district hospitals, according to their need and the number of patients treated at their facilities.

In total, 129,200 tablets of phenobarbital 100mg; 3,470 tables of phenytoin 100mg and 37,000 tables of carbamazepine 200mg were provided. The AED supply aims to establish the revolving drug fund for referral, provincial and district hospital in first three months. Presently, 1,112 PWE are being managed at referral, provincial and district hospitals (Table 1).

The International Narcotics Control Board (INCB) allows an annual quota of 25 kg of raw phenobarbital to Lao PDR. This allows the production of 245,000 tablets per year (sufficient for around 670 annual adult treatments). Those who benefit mostly live in urban areas.<sup>8</sup> The project's provision of AEDs has resulted in an

**Table1: Cumulative number of people living with epilepsy (PWE) accessing treatment, reported by central, provincial and district hospital (2011-2014)**

Hospital / province	Number of PWE
Mittaphab hospital	72
Sethathirath hospital	316
Vientiane capital	34
Vientiane province	283
Luangprabang province	145
Luangnamtha province	103
Savannakhet province	9
Champasak province	109
Sékong province	41
Total	1,112

increasing demand for AED at the national level, especially, in remote areas, including provincial and district hospitals.

## **DISSEMINATIONS OF INFORMATION ABOUT EPILEPSY**

Information on epilepsy has been broadcast by the mass media since 2011. It aims to combat discrimination against PWE by raising public awareness and knowledge of epilepsy. Lao APE supports daily radio spots and weekend television spots. A song for PWE was created by a renowned Lao singer. Pamphlets and posters on epilepsy are displayed at epilepsy consultation units in central, provincial and district hospitals. A telephone hotline is mentioned in all promotional material. The project receives an average of two consultations per day through this hotline. Finally, a field survey showed that the activities, including mass media, have improved knowledge of epilepsy among the public.

## **CONCLUSION**

Lao APE is at beginning in the long process to establish a strong medical network to treat epilepsy in Laos. It relies on the strong participation of non-governmental organizations in order to improve access to treatment of PWE. Activities performed have increased the number of PWE who have access to treatment. However, the challenges of a national program for PWE are still numerous. Overcoming these challenges requires further implementation of the strategies that have been implemented by the team, mainly: (i) information programs to increase public awareness through a variety of means, such as charity concerts and information campaigns in schools; (ii) dissemination of information on epilepsy at the community level; (iii) promotion of economic support of PWE who live in difficult conditions; (iv) encouragement of PWE to become association members.

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