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Brief Communication

A collaborative effort to establish a comprehensive epilepsy program in Peru

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ABSTRACT

We report the achievements obtained, over a period of 4 years, by the collaborative partnering effort of the Epilepsy Program at Western University in Canada and the Instituto of Ciencias Neurologicas in Lima, Peru, building an epilepsy program in Peru.

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1. Introduction

Peru is located in western South America (Fig. 1) and has a population of more than 29 million people, with an estimate of more than half a million of people with epilepsy (prevalence estimate of 17.8 per 1000 people) [1]. Even though it is believed that the most common cause of epilepsy in Peru is neurocysticercosis, this is most likely only true for its rural areas, particularly in the north [2]. The capital of Peru is Lima, with a population of 8.5 million people, including an estimate of more than 150,000 people with epilepsy and possibly 45,000 people with medically-intractable epilepsy. Despite these large numbers, there has not been a formal comprehensive epilepsy program in Lima, or in other parts of the country, until the end of 2011.

Of those patients with medically-intractable epilepsy, a smaller proportion continue to have seizures despite the use of all available antiepileptic drugs (AEDs) in the country, while most of them do not even have access to adequate care and the associated adequate treatment. Quality of life is severely disrupted, not only for them but also for their families, given that stigma is still a very prominent issue, particularly in the rural areas, where it is still believed that epilepsy is the result of divine punishment [4]. Lack of education and work is a common feature in this population as well.

* Corresponding author. E-mail address: Jburneo2@uwo.ca (J.G. Burneo). As is the case with all medical care in Peru, epilepsy care has been provided by general neurologists working in a three-tiered system: private (only affordable by those with private medical insurance, a population located in more affluent urban areas), the social security system or ESSALUD, and the public system (financially sustained by the central government). There is no consistent management plan for patients with epilepsy. Although there are no formal data, it is believed that the treatment gap is high, based on studies performed in other countries of similar income [3].

The surgical treatment of epilepsy in Peru has been virtually non-existent. Individual efforts have resulted in isolated surgical interventions for patients with epilepsy, without adequate video-EEG monitoring, particularly in the ESSALUD system.

Despite the existence of large hospitals and medical centers with adequate neurological expertise in major urban centers, no comprehensive epilepsy centers, particularly with prolonged video-EEG capacity, had existed in Peru before 2011. The management of medicallyintractable epilepsy simply did not exist.

2. The birth of the Peru-Canada collaborative work

With the support of the "Partnering Epilepsy Centers in America" program (PECA), supported by the North American Commission of the ILAE, the Western University Epilepsy Program in London, Canada, paired with the Department of Epilepsy at the Instituto Nacional de Ciencias Neurologicas (INCN) in Lima, Peru.

The INCN, located in Lima, is a major referral center for the treatment of neurological conditions within the public system. It is a highly



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Fig. 1. Map of Peru. Taken from: http://www.worldatlas.com/webimage/countrys/samerica/pe.htm.

specialized center with more than 30 neurologists, most of them with formal subspecialty training, as well as 10 neurosurgeons. The center has independent wards for the care of movement disorders, neurovascular diseases, neuro-infections, and epilepsy, among others. The Canadian Epilepsy Program made an initial contact with the INCN in 2008. Since then, these two institutions have been working together through workshops, mutual visits to Peru and London, and online review of cases, among other activities (See Table 1). The main



Fig. 2. A picture of the initial workshop on video-EEG delivered in Peru in 2008.



Fig. 3. A picture in the OR during the performance of the first ever temporal lobectomy in Peru.

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