

# International Issues: Neurology mission in the Ecuadorian Amazon rainforest

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The article “An epileptologist brings EEG to the Ecuadorian Amazon jungle” in the December 2009 issue of *Neurology Today* caught Dr. Laccheo’s attention. She contacted Dr. Espinosa, an Ecuadorian neurologist trained in neurophysiology and epilepsy in the United States. Dr. Espinosa chairs a nonprofit organization providing free health care in Quito, and he leads a mission to provide health care in rural Ecuador. We participated in providing neurologic services to an underserved population in rural Ecuador in April 2011 during Dr. Laccheo’s last year of residency.

Ecuador ranked 97th among 175 countries in the world according to the United Nations’ Human Development Index in 2003—the second to last in South America. Thirty-one percent of the population lives in extreme poverty, with an income of less than 1 dollar per day. In the Amazon region, 66% lack access to a sewage system and 44% to electricity. Up to 50% of children under age 6 suffer from malnutrition and the mortality rate of children under 5 is 24/1,000.<sup>1</sup> Thirty percent of the population lacks regular access to health services and two-thirds have no health insurance. Indigenous ethnicity is a strong predictor for less frequent use of health care services in Ecuador.<sup>2</sup>

Our neurology mission took place in Tena, located in a rural Amazon rainforest region east of the Andes Mountains at the junction of the Rio Tena and Rio Paño, about 200 km (5 hours drive) away from the capital, Quito (figure). Tena has a population of 45,000 that is mostly derived from the descendants of those who fled the Spanish invasion in the Andes in the 16th century. The thick rainforest is home to many natives and remains isolated from the rest of Ecuador with limited access to major cities and health care. The local hospital of Tena, Jose Maria Velasco Ibarra, has a 120-bed capacity and is the largest hospital in Napo province. Neurologic services are unavailable despite its large population, and there is no intensive care unit at the hospital. Criti-

cally ill patients are transferred to the major hospitals in Quito; however, without the availability of transportation by air, the 5-hour ambulance drive is a life-threatening challenge to those with major neurologic emergencies. Next to the hospital is PediHabilidad, the only rehabilitation clinic for children with disabilities in Napo province, founded in 2006 by an American trained physical therapist, Nicole Falcone. It started with 6 children with cerebral palsy and has grown to providing free rehabilitation services for over 400 children. It was Ms. Falcone who approached Dr. Espinosa to provide neurologic consultations to her patients, and this led to the first Neurological Brigade in April 2009. April 2011 was the third neurology brigade to Tena, bringing a total of 19 volunteers from the United States, including staff neurologists, a neurosurgeon, EEG technicians, various support staff, and the authors.

Data from the first mission in 2009 showed that 36% of patients had epilepsy (147 out of 475), though only 10 patients underwent neurologic imaging. A total of 101 patients were newly diagnosed with epilepsy, 42 patients had not received treatment for their epilepsy, and 71 patients were on inappropriate therapy. The calculated epilepsy treatment gap (patients evaluated with epilepsy not receiving treatment) was estimated to be 77%–80%, although the true gap may be larger in the community if one considers referral bias.<sup>3</sup> A total of 1,078 neurologic consultations were seen (table), and 221 EEGs were performed during 3 annual medical missions combined. The rate of abnormal EEG findings in the epilepsy patients was 65% (epileptiform discharges and focal slowing), which seems to be higher than what we typically find in developed countries.<sup>4</sup> Our higher rate of abnormal EEGs may be explained by referral bias, lack of neurologists in the area, and, more importantly, because epilepsy and EEG abnormalities are more prevalent in the developing world.<sup>5</sup> In Tena, carbamazepine is most frequently used (>45%), followed by valproic acid (35%), and then

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**Figure** Map of Ecuador



The red dot indicates the location of Tena, where the neurologic missions take place. Map modified from the CIA World Fact Book, available at <https://www.cia.gov/library/publications/the-world-factbook/>.

phenytoin (10%). Phenobarbital, which is widely used in other developing countries, is used in only 5%<sup>3</sup> of epilepsy patients because phenobarbital is considered a controlled substance in Ecuador requiring a special prescription. According to a statement by the World Health Organization, in conjunction with the International League Against Epilepsy and International Bureau for Epilepsy, globally up to 85% of people with epilepsy are either inappropriately treated or not treated at all.<sup>6</sup> Increased epilepsy rates in Ecuador may be partly attributed to parasitic and other infectious diseases as well as poor perinatal care. The mortality rate due to epilepsy may be as much as 3 times greater in the developing world (6.3 in Ecuador as compared to 2.1 in Rochester, MN).<sup>7</sup>

**Table** Total number of neurologic cases, epilepsy diagnosis, and EEGs performed

	Neurologic cases	Epilepsy diagnosis, n (%)	EEG performed
Mission 1: 2009	475	147 (31)	127
Mission 2: 2010	350	131 (37)	35
Mission 3: 2011	253	134 (52)	59
<b>Total</b>	<b>1,078</b>	<b>412 (38)</b>	<b>221</b>

Our outpatient neurologic consultations took place using clinic rooms at Hospital Jose Maria Velasco Ibarra. Patients were mostly Native Indians (Quichuan) from remote villages, who often walked or canoed 3 hours, sometimes carrying their disabled child in a sling to seek medical care in Tena. Even the elderly often had to be carried on family members' shoulders in order to reach the clinic. In one representative case, a mother brought a 1-year-old girl wrapped in a sling. She was born underweight and had multiple convulsive episodes starting at 6 months of age, though no diagnostic evaluation had been done and she was not being treated with anti-convulsants. She was flaccid except for facial twitching. An EEG confirmed she was having intermittent rhythmic bursts of high-amplitude anterior predominant 3-Hz spike and slow wave discharges. Because perinatal screening was not routinely available in Ecuador, concern was high for a potential reversible metabolic cause. Another mother entered the examination room tearful that the shaman was unable to cure her daughter's spells of unresponsiveness and staring, and that she was no longer able to attend school. EEG confirmed absence epilepsy. As we explained the diagnosis, treatment, and prognosis, the mother again cried and shook my hands repeatedly, saying "muchas gracias"—I had never been appreciated this much before.

It appeared to me that there is also social stigma to neurologic disease in Ecuador that may contribute to the medical treatment gap—neurologic disease can be perceived as "mental illness" or a "spiritual problem." Seeking cures by traditional remedies and rituals administered by the local shaman appears to be a common practice. Seizures can be seen as an attack of hysteria or possession by devils and are treated by beating with ortiga, a poison ivy-like plant, as a punishment. Children with physical impairments may be offered treatments in the form of massage with snake oils or cleansing using eggs, with the aim that this will clean or cure the impairment. Sadly, children with motor or cognitive deficits do not attend school and are isolated from the rest of society. Also, this society has little ability to adapt to children with developmental disabilities, due to a lack of assistive devices such as wheelchairs.

Much of our work involved not only offering medical diagnoses and treatments but also raising public awareness of neurologic disease. We participated in local and national television interviews and addressed the need for neurologic care in rural Amazon areas. We held neurologic seminars for local health care providers to educate them in the recognition and management of common neurologic conditions such as epilepsy, hydrocephalus, and cerebral

palsy. We worked closely with local internists and pediatricians so that continuity of care for the patients could be provided effectively after the US volunteers leave. Dr. Espinosa travels periodically to Tena, and also provides teleconferences and e-mail consultations with local primary care physicians between annual brigades. The neurology mission of Tena is a model for other developing countries where access to neurologic care in remote areas is not available. As a resident, I was able to learn how to best treat patients with limited resources, and I began to appreciate how fortunate I am to provide care in a high-resource country.

On my last day in Ecuador, I visited the Museo Fundacion Guayasamin in Quito. Oswaldo Guayasamin was a 20th-century Ecuadorian sculptor and painter. His mother was mestizo (mixed heritage) and his father was indigenous. "Guayasamin" means "white flying bird" in Quichuan, an indigenous language of the Andes.<sup>8</sup> He experienced the struggles of underprivileged indigenous people. His work is dedicated to social and political awareness of his people who have been ignored and exploited. The paintings portray faces of sadness and agony illustrated with strongly contrasting colors. Among his paintings, "Madre y Niño," depicting a feeling of tenderness and affection of a mother and child despite adversity, reminded me of many patients and families I saw in Tena. An inscription in the museum stated "Yo llore porque no tenia zapatos, hasta que vi un niño que no tenia pies" ("I cried because I had no shoes, until I saw a child with no feet"). The truth of this statement is difficult to realize until you see with your own eyes the difficulties faced by the people of Tena.

Trainees who wish to obtain more information about this program and opportunities to get in-

involved should contact Patricio S. Espinosa, MD, MPH; e-mail: ps.espinosa@cien-ecuador.org; Internet: www.cien-ecuador.org.

## AUTHOR CONTRIBUTIONS

Dr. Laccheo drafted the manuscript. Dr. Espinosa revised and edited the manuscript.

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## DISCLOSURE

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