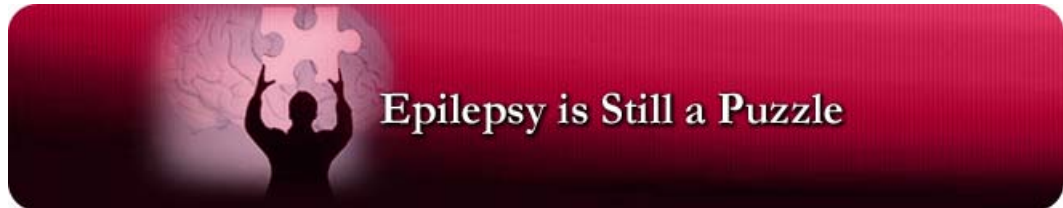


<b>REGIONAL COMMISSIONS</b>	AFRICA	ASIA AND OCEANIA	EASTERN MEDITERRANEAN	EUROPE	LATIN AMERICA	NORTH AMERICA
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Epilepsy is Still a Puzzle

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*Epigraph* Volume 14 Issue 1, Winter 2012



From The Information Officer



As we close out 2011 and 2012, it is a good time to consider some of the major events that have happened in the epilepsy world in the last year or two, as they should influence how the epilepsy community focuses its attention on the coming year and beyond. As in every year, there are the good and the bad, but even in the bad, there are rays of hope and lessons to be applied. On the good side, the last year has seen an unprecedented advance in the attention epilepsy has received from governmental bodies. On the bad side, there were the well publicized natural disasters. In these disasters, epilepsy, as is frequently the case, received little attention amidst the chaos, so people with epilepsy, often cut off from their medications, were left to fend for themselves.

In this issue of *Epigraph* there are four articles from our colleagues outlining the national responses to the recent earthquakes and floods in Japan, Chile, Pakistan and Haiti. Each country faced unique challenges based on the nature of the disaster, the geography, the physical infrastructure and the medical resources. For each country, in very little time, a plan was created for dealing with the issues faced by epilepsy patients who were suddenly deprived of access to medications and medical care. In the midst of caring for people when the usual structures of a society collapse, many lessons were learned, and these important lessons are outlined by Drs. Nakasato (Japan), Aziz (Pakistan), Acevedo (Chile) and Carmant (Haiti). Among the most important lessons was those who plan for disasters must be aware of the critical needs of people with chronic disorders, otherwise they may fall victim to neglect. Also learned was the need to have emergency supplies of antiepileptic medications in reserve so that they can be dispensed rapidly. Successful interventions in most of these countries were the result of efforts organized by national agencies and of significant involvement by non-governmental organizations and individuals who were more attuned to the specific needs of people with epilepsy. However, in some cases, assistance came from resources outside the country, as what little infrastructure that had existed was destroyed. The common message in these four articles is that there needs to be a plan and allocated resources to cover the relatively modest but critically important issues faced by people with epilepsy when the medical infrastructure is disrupted. Another important message is that the epilepsy community should have a plan for assisting other countries at times of disaster. In Haiti, emergency care came from outside the country in the form of expertise and medicines. More recently in Thailand which was overrun by floods, some outside assistance came from the Japan Epilepsy Society with a donation of \$10,000 to help in the care of people with epilepsy who were suddenly cut off from the medical system. In short, we need to be aware of epilepsy needs in the time of disaster as we plan for the future.

On the very positive side of the past year was the new visibility that epilepsy has received from governments and international bodies. To start the cascade of events, at the end of 2010 Colombia passed a law protecting the rights and special needs of people with epilepsy. It was a momentous event that did not come easily, as it took an almost 40-year focused effort by Jaime Fandiño-Franky and his colleagues, national and international. In September 2011, there were two major milestones in Europe and the Western Hemisphere. The European Parliament passed the Written Declaration on Epilepsy to make epilepsy a priority for research and healthcare throughout the European Union. This Declaration, passed by one of the largest majorities ever for a written declaration, was the result of a combined effort of the IBE and ILAE through its Joint Task Force on Epilepsy, co-chaired by Mike Glynn and Emilio Perucca. At the end of September, the Pan American Health Organization (PAHO), the branch of the WHO in the Americas, passed a Strategy and Plan of Action for Epilepsy. This agreement obligates the governments in the Western Hemisphere to develop national plans that address the specific needs of patients with epilepsy as well as to enhance epilepsy related research. This result came from the considerable effort of Jorge Rodriguez (PAHO), Carlos Acevedo (IBE) and Marco Medina (Honduras).

These three major events have given unprecedented hope to people with epilepsy, their families and the professionals who treat them. However, these agreements will mean nothing without the sustained efforts of the epilepsy community. None of these documents establishes a single program or allocates any new resources to epilepsy, and in our current day to day practice there will be no changes unless we work to make them. What these agreements do provide is access to governments that have agreed

to make epilepsy a priority, and they open a door for the epilepsy community to work with government agencies. It is, however, up to us to take the initiative and begin the discussions with our national health and research agencies. It will be our responsibility to educate our colleagues in the health sector about the unique issues created by epilepsy and how the issues can be addressed. It will be a lengthy process that will take a number of years, but we have to take the lead. Contact your national Chapter and ask what is being done and how you can help make improved epilepsy care and research a reality in your country. And don't forget to include plans for natural disasters.

Edward H Bertram  
Information Officer

### PAHO/WHO Strategy and Action Plan Developed

The countries of the Americas, with support from the Pan American Health Organization/World Health Organization (PAHO/WHO), will work together to create national programs for the care and treatment of epilepsy, a neurological disorder that affects some five million people in the Americas.

Only 10 countries in the hemisphere currently have a national epilepsy care program in place. At a meeting of the 51st PAHO Directing Council this week, representatives of PAHO/WHO Member States approved a strategy and plan of action that calls for the creation of similar programs in the rest of the Region's countries, setting a target of 20 countries with such plans by 2015 and 30 by 2020. For more information go to <http://www.ilae.org/Visitors/News/paho.cfm>

Health authorities from the countries of the Americas agreed to make epilepsy a priority issue and to strengthen the health sector response to the disorder, with a focus on primary healthcare.

The strategy also addresses gaps in treatment: currently more than 50 percent of people with epilepsy in Latin America and the Caribbean do not have access to appropriate treatment and care.

The strategy and action plan was developed by PAHO/WHO based on a consultative process with partners including the International League against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), ministries of health and other national organizations, WHO's Department of Mental Health and Substance Abuse, and other experts.

Under the new strategy, countries will work to:

- Make epilepsy a national health policy priority, implementing national programs that are adapted to conditions in each country
- Strengthen legal frameworks to protect the human rights of people with epilepsy and to ensure effective enforcement of relevant laws
- Promote universal and equitable access to medical care for all people with epilepsy by strengthening primary care systems and integrated service networks
- Ensure the availability of the four antiepileptic drugs considered essential for treatment of the disorder
- Strengthen neurological services to support case detection and management at the primary care level, ensuring adequate distribution of the necessary auxiliary diagnostic media
- Support effective participation by the community, patient associations and family members in activities designed to improve care for people with epilepsy
- Consider the strengthening of human resources as key to improving national epilepsy programs
- Promote intersectoral and educational initiatives to combat stigma and discrimination against people with epilepsy
- Close the information gap in the field of epilepsy by improving the production, analysis, and use of information, including research
- Strengthen partnerships between the health sector, other sectors, and nongovernmental organizations, academic institutions, and key social actors.

### Epilepsy Care After The March 2011 Earthquake And Tsunami in Japan



Dr. Nobukazu Nakasato  
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University School of Medicine, Sendai, Japan

A catastrophic earthquake and tsunami occurred on 11 March 2011 in the Tohoku district, on the northeast coast of Japan. Roughly 20,000 people are dead or missing, mainly as a result of the tsunami. In contrast, only about 5,600 were injured, which is a relatively small number for such a huge disaster. However, 200,000 people were obliged to move to evacuation centers. Many people living in the devastated area were suffering from chronic diseases, including epilepsy, and were abruptly deprived of their medications due to the sudden nature of the disaster. The tsunami affected a huge area including more than 600 km of coastline, and resulted in severe disruptions to the transportation system and critical shortages of gasoline for about two weeks (Fig. 1). I did not personally see all sufferers, but can imagine that many epilepsy patients faced healthcare problems that resulted from the sudden disruption in the supply of their medications.



Figure 1. Takata Hospital, Rikuzentakata City, 2 April 2011. The tsunami reached to the level of the broken line.

It was clear that special actions were needed to reach our epilepsy patients and assure that they were receiving their medications. Tohoku University in Sendai was in the area of the disaster, and it became a major center for coordinating medical care in the region. On 17 March, six days after the tsunami, I began publishing updates via e-mail bulletins entitled "Epilepsy Disaster" on a twice-daily basis or more for the first two weeks. The goal of these bulletins was to keep everyone informed of the conditions in the region of the disaster and of the critical needs of our epilepsy patients. Many people subscribed to the bulletins and redistributed our messages to their colleagues. Primary subscribers included members of the Japan Epilepsy Society (JES), patients and their families, government officials, pharmaceutical companies, and media representatives. The bulletins covered the medical need lists of hospitals in the devastated areas, summaries of daily briefings in Tohoku University Hospital, and emergency reports from many medical teams. Some physicians who obtained information from the bulletins went as volunteers to the coastal area to help provide care. Some officials of the Ministry of Health, Labour and Welfare took direct action to help drug deliveries. News media quickly came to my office and then went to the devastated area to gather and report information about emergency healthcare.



Figure 2. On-site meeting of the Disaster Countermeasures Team, Japan Epilepsy Society, 19 June 2011, at the Department of Epileptology, Tohoku University School of Medicine, Sendai.

The response of the JES was quick. A disaster headquarters was set up in the Department of Epileptology, Tohoku University (Fig. 2). Antiepileptic drugs donated by JES member hospitals and pharmaceutical companies were first delivered to the disaster headquarters in Tohoku University, then distributed to the affected hospitals until the normal supply system of wholesale dealers could be restored (Fig. 3). Although increased numbers of patients with seizure disorders presented to the hospitals of devastated area because of increased seizure activity or seizure-related injuries, a relatively small number of patients suffered Status Epilepticus in the affected area.

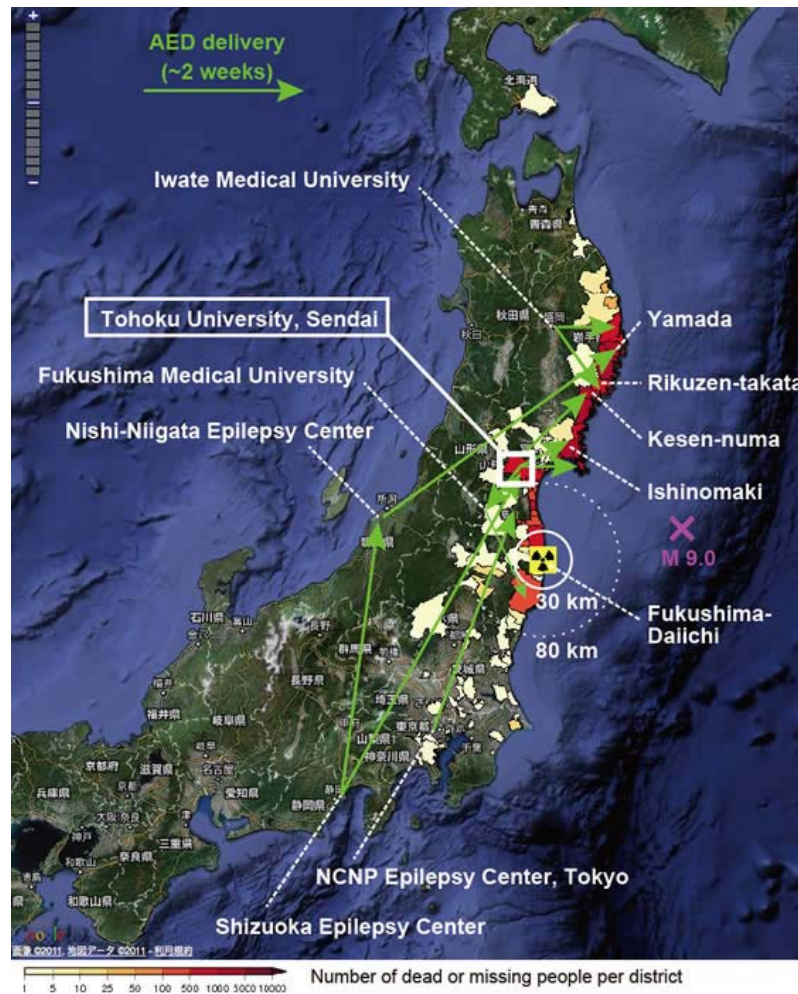


Figure 3. Emergency antiepileptic drug delivery operation run by the Japan Epilepsy Society for the first two weeks after the disaster. The green arrows indicate the path that AEDs took from medical centers outside the tsunami region to the local distribution centers Dr Otsuki from the Epilepsy Center, National Center of Neurology and Psychiatry in Tokyo, transported antiepileptic drugs (AEDs) to hospitals in and around Sendai City. The Shizuoka Institute of Epilepsy and Neurological Disorders and Nishi-Niigata Chuo National Hospital formed a joint caravan team to deliver AEDs to the Yamada area in the Iwate Prefecture. A large amount of AEDs transported from the Shizuoka Epilepsy Center to Tohoku University in Sendai was distributed to hospitals in Ishinomaki, Kesen-numa and Fukushima areas. Map provided by Google indicates number of dead or missing people per district in red to yellow color.

Several days after the disaster, new problems were exposed. Some patients would not go to shelters because they wanted to hide their seizures. Many patients complained that they had no one to talk to about their problems. To respond to these problems, Shizuoka Epilepsy Center opened an "Epilepsy Hot Line" for telephone consultation. The Japan Epilepsy Association also started a telephone consultation service to answer questions of patients and their families. This service which grew out of disaster should continue to be run by non-profit organizations in the future. I believe that the UK "Epilepsy Helpline" project is a good model for us.

Now, after half a year has passed we have learned much more about the needs of our patients. I believe that the most important issue is education about epilepsy care among the general public and physicians without expertise in epileptology. The local FM radio station in the coastline area hosted JES members for a regular Monday morning program for three months entitled "Feel safe to learn about epilepsy, a disease close to home." Lectures about epilepsy have been held frequently not only for local members of the JES but also non-JES physicians and the general public. A telemedicine system is under construction to provide remote epilepsy clinical care with epileptologists in Tohoku University and patients in local hospitals along the coastline. We are trying to leverage the experience of this awful disaster into improved epilepsy care not only in the Tohoku area but also all over Japan



### Epilepsy and Natural Disasters in Pakistan



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National Epilepsy Center  
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Pakistan was singularly struck by two of the largest natural calamities in the world within five years (an earthquake in 2005 and river flooding in 2010) with now the third ongoing (in 2011).

An **earthquake** of 7.6 Richter scale (RS) jolted the Himalayan areas of Pakistan on 8 October 2005 at 08:52 am; the epicenter was approximately 100 km from the capital city of Islamabad. The timing was significant as it annihilated an entire generation of children and young people attending schools and colleges at that moment. Actually this was a series with >150 earthquakes (RS 4.6-6.2) in the first 24 hours and >975 earthquakes (RS 4 - 5.8) in the following 20 days. This resulted in extensive destruction; **73,338 dead, 288,309 injured, >5 million homeless** and all local health facilities destroyed. The accompanying rain, hailstorms, massive landslides and collapsing bridges severed all communication. A mass exodus of people to flat lands and thousands of incoming volunteers caused massive traffic clogs on the few narrow mountainroads; resulting in delay in rescue work by three to five days.



Relief help was possible mostly on foot, some by mule-trains and a few helicopters.

**Massive floods** hit Pakistan in July 2010. The 3,180 km long mighty Indus River remained in high floods for ~2 months inundating its entire drainage area of 1,165,000 sq km and continued devastation affecting 18 million people (total Pakistan population 180 million); submerging 132,000 sq km area, destroying 1.7 million houses and 1985 immediate deaths. However, delayed mortality and morbidity continues to date (October 2011) with several thousand adults and children affected by Acute GI problems, ARI, Malaria, Skin, Dengue, AFP (Polio), Measles, VHF, Tetanus and Severe Acute Malnutrition (SAM). This was not simple "flooding" as understood by most; it was termed ". . . a *Slow-Motion Tsunami*. *Its destructive powers will accumulate and grow with time*" by the Secretary General of the United Nations and the International Red Cross.



The people still recovering from last year's floods are faced with a new wave of floods again. Due to the massive extent of the floods, rescue and relief work has not put the slightest dent to the suffering of thousands.

**Epilepsy care** unfortunately, under such disastrous catastrophes gets no priority, even in the more advanced countries. An extensive internet search does not mention any data on epilepsy during almost any such calamity in the world, including Pakistan. The only exception is a mention of epilepsy (without data) in one WHO report on the 2005 earthquake, where epilepsy was grouped as "Organic Brain Disorder including epilepsy" (*October 2005 Earthquake: Mental Health Psychosocial Support in & Six Months Emergency of Health Relief Operations, Pakistan*. WHO, Pakistan, 2005-06.)



In Pakistan, we have been fortunate in providing some assistance through volunteers, mostly belonging to the NGO, Comprehensive Epilepsy Control Programme of Pakistan (CECP), offering their help by becoming part of major general medical relief camps.

The unpublished local NGO epilepsy care data is summed in Tables 1 and 2. Table 3 shows the estimated people with epilepsy affected by the natural disasters whilst Table 4 compares the outcome of the two natural disasters in Pakistan, with others in recent times.

Table 1: Earthquake 2005: Summary of epilepsy care data provided by volunteer neurologists who were part of medical relief camps held in the close vicinity of the earthquake epicenter. A term 'Earthquake epilepsy' was coined by some specialists for the new onset epilepsy cases reported; 15 to 90 days AED supply was provided. Epilepsy-related mortality was not reported but only related.

Volunteer Neurologists	Total Pts (-)	PWE (-)	Epilepsy Presentation					Epilepsy-related mortality
			Controlled & taking AEDs	Recurred/ worsened due to non-availability of AEDs	Recurred / Worsened whilst taking AEDs	New	SE	
04	4200	377	128	77	15	57*	0	1**

Table 2: Floods 2010: Summary of epilepsy care data provided by volunteer neurologists who were part of medical relief teams camped along the length of Indus River. AED supply for 0-30 days and epilepsy related morbidity was related, not reported.

Volunteer Neurologists	Total Pts (-)	PWE (-)	Epilepsy Presentation					Epilepsy-related mortality
			Controlled & taking AEDs	Recurred/ worsened due to non-availability of AEDs	Recurred / Worsened whilst taking AEDs	New	SE	
10	134,145+	506	181+	208+	1+	73+	3	2*

Table 3: Estimated people with epilepsy that were affected by the natural disasters in Pakistan. Prevalence rate of epilepsy in Pakistan is ~1% of Pakistan's population of 180 million (Aziz H. et al. *Epilepsy in Pakistan: Epilepsia* 1994 35(5):950-8).

	Population Affected	Estimated PWE	Total seen (CECP + others)	PWE
Earthquake 2005	5 million	50,000	4,200	377 (9%)
Floods 2010	18.1 million	0.18 million	134,145	506 (0.4%)

Table 4: Comparing the major natural disasters in the world in the last five years, the Pakistan earthquake and the floods have had the maximum toll on humans as well as property. The United Nations has described the 2010 Floods as "More than combined total of 2004 Indian Ocean Tsunami, 2005 Pakistan earthquake and 2010 Haiti earthquake."

	Pakistan EQ	Haiti EQ	Japan EQ & Tsunami	Chile EQ & Tsunami	Pakistan Floods	Myanmar Cyclone Nargis	USA Cyclone Katrina	Indian Ocean Tsunami
	Oct 2005	Jan 2010	Mar 2011	Feb 2010	Jul 2010	May 2008	Aug 2005	Dec 2004
Population Affected	5,000,000	3,000,000	NA	1,800,000	18,100,000	2,420,000	500,000	2,273,723
Area Affected (sq. Km)	30,000	13,226	NA	NA	132,000	23,500	NA	NA



Deaths	73,338	230,000	15,601	486	1985	84,537	1,836	238,000
Missing	NA	NA	4,968	79	NA	NA	NA	NA
Injured	128,309	300,000	5,694	NA	2865	19,359	NA	125,000
Household damaged/destroyed	600,152	250,000	774,926	190,000	1,700,000	450,000	200,000	NA
Displaced	NA	1,200,000	83,951	NA	NA	NA	NA	NA

**Lessons learned from the experiences of the natural disasters in Pakistan:**

The first ten days are crucial as chances of recurrence and Status Epilepticus are high due to varied reasons like non-availability of drugs, emotional stress, etc. In the initial chaos it is very difficult to single out epilepsy. Physical trauma and infective diseases are the priority and mostly epilepsy is never given due consideration. This is evident by the fact that there is no mention of epilepsy in any International Aid Agency Reports (except one) or that of the Health Ministry. People with epilepsy could only be helped when the neurologists became volunteer workers and joined general medical relief groups working in the field.

From our experiences in Pakistan we suggest that epilepsy caregivers must volunteer field relief work on location by becoming a part of larger medical relief groups. Provision of AEDs and sensitizing caregivers about epilepsy must also be planned.

For more images of the conditions in Pakistan following the earthquake and flood, please see the presentation ([click here](#)).



**Epilepsy and natural disasters: The Haiti Experience**



Lionel Carmant, MD  
Hospital Ste-Justine  
Montreal, QC, Canada

On 12 January 2010, on the Island of Hispaniola, in Haiti, the world stopped spinning at 16:53 p.m. Haiti was hit by an earthquake of 7.0 on the seismic scale. The epicenter was in Léogane, a small town 25 km west of the capital of Haiti, Port-Au-Prince. But most of the damage was in Port-Au-Prince, an over-populated city with more than 2 million inhabitants, but with an infrastructure built to accommodate less than 500,000 people. The result was a disastrous death toll of between 200,000 and 300,000 people.

In 2008, the ILAE's North American Commission had helped launch the first Haitian Epilepsy Clinic located within a five-minute walk of the Presidential Palace, which was destroyed by the earthquake. The clinic is directed by one of the local neurosurgeons, Dr Elie, and visited regularly by a neurologist from the North American Commission's Task Force. After the earthquake, communication was lost for two weeks, but miraculously, the clinic survived with minimal damage.



For the first two weeks after the earthquake, all communications were lost with CLIDEP (Clinique d'Épilepsie de Port-Au-Prince). During that time, neurological care was provided by the USNS Comfort, a United States of America naval hospital ship that arrived in Haiti within eight days with a neurologist, a child neurologist, two neurosurgeons and three physical therapists. They were able to see most patients with neurological injuries and requiring admissions. The most common reasons for admission were traumatic monoparesis, paraparesis and tetraparesis.

A week later CLIDEP was able to re-open despite the fact that both the epilepsy nurse and the EEG technologist had lost their homes. When originally established CLIDEP focused primarily on people from the immediate Port-Au-Prince. After the earthquake, many patients from surrounding areas sought assistance at the Clinic, as there was a large camp for survivors that was only a few minutes away from it. The clinic, in addition to its usual epilepsy clientele, served also as a general clinic offering medical as well as minor surgery services to the global population. Dr Elie's team was supported by a French group of physicians and nurses from the city of Tours, where he had previously trained. Over a two-week period, more than 400 patients were seen, equaling in 14 days, the number of patients seen in the first year of function of the clinic.

The aftermath of the earthquake for patients affected with epilepsy included increased stress and a shortage of seizure medication due to the destruction of local pharmacies and the closure of the two generic antiepileptic drug makers. This led to many breakthrough seizures and a number of the patients from the clinic going into Status Epilepticus in a setting where hospital care was largely unavailable.

In March, Dr Lionel Carmant from the North American Commission was able to visit CLIDEP equipped with a portable EEG machine given by Astro-Med to provide services at the hospital and more importantly equipped with a six-month supply of carbamazepine donated by Novartis Canada, divalproex given by Apo-Pharmaceuticals Canada and levetiracetam from UCB Canada. The free medication led to an improvement in compliance and in the number of seizure-free patients.



*A child undergoing an EEG at CLIDEP*

With the improvement of seizure control observed in most patients, comorbidity started to surface with the most important one being depressive symptoms associated with posttraumatic stress. Unfortunately, the clinic had no access to psychologists and this situation has remained unaddressed until 2012 when the Pan American Health Organization (PAHO) intervened to improve mental health care in Haiti, making medication, including seizure medication, available at acceptable cost to the population.

In conclusion, we have learned a great deal from this catastrophe. The most important thing is that the clinic needs to keep a month's worth of seizure medication in reserve to avoid national shortages. We have also started giving medication to patients with limited funds. Due to its minimal cost, phenobarbital is the medication given to these patients. We also need to coordinate our activities better with international initiatives in the acute stages. Finally, we realized that we need to address comorbidities in this under-privileged population as well as in developed countries. If another natural disaster occurs, CLIDEP will be better prepared to face it.

CLIDEP wants to take this opportunity to thank all ILAE members who contributed to the American Epilepsy Society driven fundraiser, which provided more than \$15,000 to enable the clinic to provide salaries for the EEG technologist and epilepsy nurse who had lost their homes and to pay our rent and provide services while 95 percent of the clinic's patients could not pay for medical services or medication.



*The Cathedral of Port-Au-Prince, a five-minute walk from the epilepsy clinic before (above left) and after (below) the earthquake.*



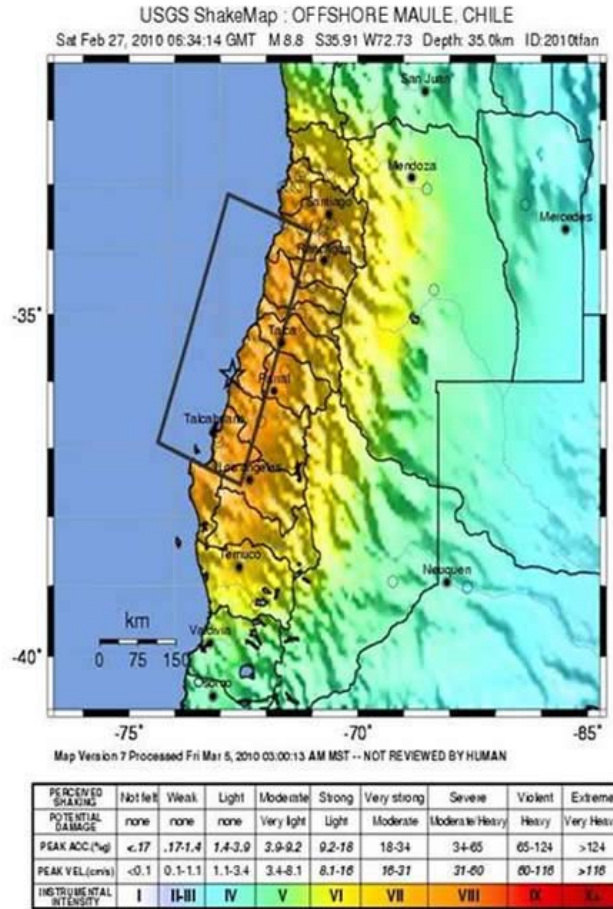
### Earthquake in Chile



Dr Carlos Acevedo  
IBE Secretary General  
President of the Chilean League Against  
Epilepsy

On 27 February 2010 at 3:34 a.m. a magnitude 8.8 Richter scale earthquake and tsunami occurred in Chile that lasted 1 minute 30 seconds in the epicenter and 2 minutes 45 seconds in Santiago, the capital. The earthquake covered the central region of the country from Valparaiso to the Araucania, a distance of 620 km, and it affected 13 million people or 80 percent of the population of Chile. Its epicenter was in the sea near the coast. The physical consequences of the earthquake were 525 dead and 79 missing, 500,000 destroyed or severely damaged houses and 2,000,000 homeless. The earthquake of February 2010 was one of the six most severe ever registered, and it was 31 times more intense than the one registered in Haiti a month earlier that caused over 250,000 fatalities. In the first week after the earthquake there were twelve aftershocks (between 6.0 and 6.9 intensity on the Richter scale), seven of which occurred within the first 24 hours after the earthquake. Thirty-five minutes after the earthquake

there was a tsunami. The first two waves were 8 and 10 meters respectively, and they razed coastal towns causing an additional 300 deaths and the disappearance of 25 people. Most of these victims had just ended their summer coastal camping vacation.



**Immediate consequences**

Electricity: Blackouts due to electric towers collapsing and damage to power plants. Within nine hours the power was returned in Santiago, but in the rest of the country it was delayed some days and the last locations to recover were along the coast.

Drinking water: Limited availability with 87 percent of the supply restarted in the first 72 hours except in areas where the tsunami hit. The affected population was supplied with water by trucks provided by the state and private companies.

Telecommunications: problems were caused by falling towers and cables. The home telephone line network was most affected. Cellular service dropped by 68 percent but also in the first hours there was a system collapse due to excessive calls. Many lives were saved by communication via mobile phones. Within the first week communications were completely restored.

Infrastructure damages: 1,200 damaged structural points including bridges, roads, port terminals and airports. Emergency overland connections to central Chile were reestablished within 48 hours.

Hospitals destruction: there was a loss of 40 percent of total beds available in public health services.

The economic losses: damage in houses, hospitals, schools and infrastructure is estimated at USD\$ 30,000,000.

Public safety: In the hours following the earthquake robberies and lootings to commercial stores took place as supermarkets and houses were abandoned by their owners. There were hundreds of inmates of the destroyed jails who escaped. Next day on February 28th a state of emergency was decreed and the army took part in it guaranteeing the public security and establishing curfew.

Supplies: As the affected region was a predominantly agricultural area, there were no food shortages. An unexpected problem was the lack of money because the banks were closed and the ATMs were broken, so many people did not have cash for several days.





**Response of the Public Health System**

In Chile, public health systems cover approximately 75 percent of the population. At the time of the earthquake there was no contingency plan at the public health system to address chronic problems such as epilepsy in disaster situations.

**What was done?**

The best care whenever possible is provided in hospitals, doctor's offices or outdoor clinics, but in many areas the hospital destruction was total. In addition many healthcare personnel and their families were also injured by the earthquake. The availability of antiepileptic drugs (AEDs) was uncertain, but at least in some cases it was possible to rescue them from the ruins of the offices. In other cases they were made available by donations or resorting to medical samples. Healthcare providers no longer had patient files that were lost so medications had to be given only based upon the information provided by the patients or their families. In many cases doctors in the affected areas had to act on their own initiative and, when was necessary, they transferred patients to hospitals that were functioning. This earthquake made it apparent that the concept of catastrophe and plans to address disasters were focused primarily on saving lives, with teams of surgeons, orthopedic surgeons, intensivists and neurosurgeons. However, these plans ignored the reality of people living with chronic illnesses such as epilepsy.

**Response of the Chilean League Against Epilepsy (LICHE)**

LICHE is a self-funded, non-governmental organization that covers much of the country and manages drug banks, including some located in earthquake-affected cities: Santiago, Curicó, Talca, Temuco, and Concepción. Each drug bank has a staff that consists of : a pharmaceutical chemist, pharmacy assistants, volunteer medical and nonmedical professionals such as social workers. Each bank has a stock of medications that includes all existing AEDs in Chile as well as commonly prescribed anxiolytics, hypnotics and antipsychotics.



**Actions Taken**

LICHE took a number of actions including shipment of clothes, water, blankets, food, batteries and AEDs to the affected areas.

During the first week after the earthquake, all those people who requested AEDs, got them for free without medical prescription. In cases requiring transport from one city to another, LICHE funded the trip. Radio and the press informed the public of the existence of this assistance.

#### **Actions taken by private institutions**

There were many initiatives by private institutions. One such effort was by a Medicine Faculty that developed an emergency team which was sent to a locality (Iloca) affected by the earthquake and tsunami. The team was formed by pediatricians, internists, trauma surgeons, nurses and auxiliaries. In the first two weeks they carried out 772 medical interventions of which 15 percent were for chronic diseases and psychiatric disorders. After two weeks of steady work it was necessary to incorporate a mental health team that continued its local support for several months, essentially for anxiety disorders and posttraumatic stress.

#### **Contingency Plan for Natural Disasters**

Contingency plans for natural disasters, should suit the type of disaster, its magnitude, the level of a country's development, population density and taking into account geographical factors. Such plans will depend on whether the disaster is along the coast, or in such unique environments such as desert, mountains, jungle, cities or suburbs. Plans will also have to take into account the type of natural disaster: earthquake, tsunami, flood, hurricane, volcanic eruption. The development of a contingency plan needs to take into consideration a number of factors including working with the appropriate health authorities. In working with them one has to start with information on the magnitude of the problem (number of possible affected patients or a listing of them). There must be an effective system of transportation to get assistance to the affected areas, and, if professionals are coming from the outside a means for credentialing them as well as defining their scope of work.

Ideally there should be teams already created that include physicians trained in the neurological issues associated with catastrophes as well as nurses and pharmacy assistants. In addition, there should be a stock of AEDs for emergency use so that they can be supplied quickly. Having a means for tracking the type of care provided as well as the frequency will assist in future planning.

#### **Priorities for natural disasters**

- Availability of AEDs and rescue medication to treat cases of Status Epilepticus.
- Have medical specialists and physicians trained in management of epilepsy
- Ambulance transport of patients difficult to manage
- Inform the public how to access AEDs and necessary medical care

#### **Prevention Strategies**

It is very important to educate patients on the importance of regular intake of AEDs and patients should carry a card that identifies them and indicates which AESs they take and the dosages. Ideally, the patients should always have an emergency supply of a one-week reserve of drug treatment. However, to accomplish such a goal it is necessary to convince the authorities and the insurers about the importance of considering chronic diseases such as epilepsy as a priority disease after a natural disaster. Clearly, this requires an established emergency plan to deal with natural disasters, and it is necessary that this plan is coordinated by government officials and health officials as well. It is also essential that institutions such as non-governmental organizations (NGOs) develop plans to support people with epilepsy in case of natural disasters. Plans specific for people with epilepsy can achieve good results. In our particular case we were fortunate in Chile as there was no mortality attributable to epilepsy.



#### **Conclusion**

The existence of emergency plans to cope with chronic diseases such as epilepsy can be very useful in the occurrence of natural disasters. Organizations such as ILAE and IBE can collaborate effectively in mitigating the effects of these disasters on people with epilepsy.

#### **Information sources**

We thank the following for providing information for this article: Government of Chile; Chilean League against Epilepsy; Faculty of Medicine of the Universidad del Desarrollo; and neurologists from the devastated area.

#### **Free webcasts of the 5th World Congress on Controversies in Neurology (CONY2011 – Asia Pacific)**

At the October 2011 Controversies in Neurology meeting in Beijing there were several debates about issues relevant to epilepsy. To see those discussions you may visit [5th World Congress](#).

### ILAE New Website Launched

ILAE is pleased to announce the launch of its newly redesigned website, at the same address as the old one ([www.ilae.org](http://www.ilae.org)). We have reorganized the website to be more logical and easier to navigate. We hope you will find the new site more effective and more visually pleasing.

New features include:

- Improved Search function
- A 'News About Epilepsy' section to keep you constantly informed about epilepsy news from around the world, and about news regarding important clinical and research developments
- Congresses related to epilepsy can be found easily
- New sections called Epilepsy Care and Global Outreach
- An 'Epilepsia' section that lists a selection of the most recent articles as well as the most downloaded articles in *Epilepsia*

Please send suggestions and comments regarding the website to Jean Gotman, ILAE Director of Interactive Media, at [jean.gotman@mcgill.ca](mailto:jean.gotman@mcgill.ca), putting "ILAE website" in the subject line.

### New Journal Announced

A new journal has been launched in Turkey. *The Journal of Pediatric Epilepsy* (JPE) launched its first issue in May of 2011. The journal, which is published quarterly in English, includes editorials, review articles, original articles and case reports. Special issues are being considered that are focused on specific topics. Suggestions are welcome and can be sent to [jpe@adu.edu.tr](mailto:jpe@adu.edu.tr). The Editor-in-Chief is Prof Huseyin Caksen at Yuzuncu Yil University in Turkey. For more information go to <http://childscience.org/html/jpe/index.html>.

### Bookstore on the ILAE Website

There has been a steady increase in the number of books published that are relevant to epilepsy that members of the League will likely find useful for their practice or research. However, keeping up with the books that are available is no easy task. To help make the job easier we have created this Bookstore as a service to our membership. In it publishers can provide information on their epilepsy-related books. They may also provide information on where and how to purchase the books. The League does not sell the books. <http://www.ilae-epilepsy.org/booksales/index.cfm>.

The Bookstore is in the early stages of evolution, and we expect to add new titles and publishers on a regular basis, so please check back frequently for new additions.

There are currently six books listed. If you have authored a book, please encourage your publisher to list their book on this website. The cost is minimal.

### Farewells Listing on Website

ILAE hosts a Web page where we commemorate our departed colleagues in epilepsy and the contributions that they have made to the field. It is our intention that this section for memorials be open to obituaries for anyone who has been active in the field of epilepsy in any capacity: clinical, social, scientific, psychological, to name but a few. There are no academic, professional or geographical requirements to be considered for inclusion in this section. There are many great things that are done locally to improve the lives of people with epilepsy, efforts that are critical in the battle against this condition. Unfortunately some of the most important contributions are done away from the limelight and may not catch the attention of the larger international community. It is the intention of this section that anyone who has been active in the field be included and have their efforts and successes more widely known. The only real criterion is that the individual worked to help relieve the burden of epilepsy somewhere in the world.

The memorial articles will be written by those who knew the person. The goal is to tell your colleagues in epilepsy who this individual was and what the contributions were. Photographs are welcome. <http://www.ilae-epilepsy.org/visitors/farewells>.

There are two parts to this section: recent deaths and archives. The latter will be publically available to allow League members to learn about those who have gone before and the contributions they made as well as to act as a resource for those who wish to look into the history of epilepsy and those who contributed to it. We look forward to your remembrances of our valued departed colleagues. Please send them or any comments or suggestions that you may have to [farewells@ilae.org](mailto:farewells@ilae.org). We will also welcome multiple remembrances from our members. The success of this project will depend entirely on your efforts to help preserve the memories and the accomplishments of our friends and colleagues.

### Upcoming Congresses and Educational Events ([www.epilepsycongress.org](http://www.epilepsycongress.org))

3rd North American Regional Caribbean Congress on Epilepsy  
17 – 18 February 2012 in Antigua  
<http://www.jlae.org>



14th Annual Meeting of the International Symposium on Surgery for Catastrophic Epilepsy in Infants  
18 – 19 February 2012  
Tetusmon Memorial Hall, The University of Tokyo, Tokyo, Japan  
<http://www.iss-jpn.info>

6th Latin American Summer School on Epilepsy  
24 February – 2 March, 2012 in Sao Paulo, Brazil  
<http://www.lasse.med.br>

9th Asian and Oceanian Epilepsy Congress  
21 – 25 March 2012 in Manila, Philippines  
[www.epilepsymanila2012.org](http://www.epilepsymanila2012.org)

Eleventh Eilat Conference on New Antiepileptic Drugs (Eilat XI)  
6 – 10 May, 2012 in Eilat, Israel  
<http://www.eilat-aeds.com> under Forthcoming Conferences

3rd Annual Congress of NeuroTalk  
18 – 20 May 2012  
Beijing, China  
<http://www.bitlifesciences.com/neurotalk2012/default.asp>

12th International Child Neurology Congress & 11th Asian and Oceanian Congress of Child Neurology  
27 May – 2 June 2012 at the Brisbane Convention and Exhibition Center, South Brisbane, Australia  
<http://www.icnc2012.com/>

22nd Meeting of the European Neurological Society  
9 – 12 June 2012  
Prague, Czech Republic  
<http://www.congrex.ch/ens2012>

1st African Epilepsy Congress  
21 – 23 June 2012  
Nairobi, Kenya  
<http://www.epilepsynairobi2012.org/>

6th Baltic Sea Summer School  
8 – 13 July, 2012 in Rostock, Germany  
Deadline for applications: 15 April 2012  
More information: Petra Novotny, Prof Peter and Jytte Wolf Foundation for Epilepsy, [petra.novotny@wolfstiftung.org](mailto:petra.novotny@wolfstiftung.org), or under BSSSE6 on <http://www.epilepsiestiftung-wolf.de/7.html>.

10th European Congress on Epileptology  
30 September – 4 October 2012 in London, UK  
<http://www.epilepsylondon2012.org>

7th Latin American Congress on Epilepsy  
14 – 17 November 2012 in Quito, Ecuador  
<http://www.epilepsiaquito2012.org>

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