



Bringing epilepsy out of the shadows in New Zealand

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Abstract

Epilepsy is a common neurological disorder. Most patients with epilepsy have seizures that are relatively easily controlled, but a significant minority of patients have seizures that are resistant to standard anti-epileptic drugs.

The New Zealand chapter of the International League against epilepsy (NZLAE) has recently been formed to improve the care of patients with epilepsy in New Zealand. NZLAE intends to work with the lay group, Epilepsy New Zealand to help raise the profile of epilepsy within the general community, and to improve access to some of the newer drugs that are not currently available here. NZLAE is also keen to promote research into epilepsy in New Zealand, and members have recently started recruiting patients for several research projects.

“The history of epilepsy can be summarised as 4000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma.”¹ So began an editorial in the *British Medical Journal (BMJ)* 10 years ago, when a joint campaign to bring epilepsy out of the shadows was launched by the International League Against Epilepsy, the International Bureau for Epilepsy, and the World Health Organization (WHO).

In the editorial, Kale pointed out that discrimination against people with epilepsy and ignorance about the disorder is worldwide. He pointed out that more than three-quarters of people throughout the world who suffer from epilepsy are not currently treated. The global campaign was launched in an effort to rectify this situation.

Epilepsy is one of the more common neurological disorders. If we assume that the prevalence of epilepsy in New Zealand is similar to that of other Western nations (0.5% to 0.7%),² then there are approximately 20,000–28,000 people in New Zealand who have epilepsy. The risk of having at least one epileptic seizure at some time during one’s life is considerably greater, with figures suggesting that by the age of 84, approximately 5% of people will have had one or more seizures.³

The situation regarding the management of epilepsy in New Zealand is certainly not as dire as it is in parts of the developing world. Yet there is no doubt that negative attitudes towards people with epilepsy are common here too. There remain many misconceptions regarding epilepsy in the general community, and funding for treatments for epilepsy is unsatisfactory.

Launch of the New Zealand League against Epilepsy (NZLAE)

In an effort to improve the management of patients with epilepsy here, a group of adult and paediatric neurologists formed the New Zealand chapter of the International League against Epilepsy (ILAE) in November 2006. The chapter was ratified at the 27th International Epilepsy Congress, held in Singapore in July 2007.

The ILAE now has chapters in 99 countries. Its goals are:

- To advance and disseminate knowledge about epilepsy.
- To promote research, education, and training.
- To improve services and care for patients, especially by prevention, diagnosis, and treatment.

The New Zealand chapter is for health professionals with a particular interest in epilepsy. It is aimed primarily at doctors but other health professionals are also welcome to join. The NZLAE is hoping to improve the care of patients with epilepsy in a variety of ways:

Raising the profile of epilepsy

There is considerable ignorance about epilepsy within the wider community, and an unacceptable degree of prejudice still occurs as a result of this lack of knowledge. Epilepsy does not have a high profile amongst those who make funding decisions regarding healthcare. This is probably, at least in part, because many patients with epilepsy are socially disadvantaged.

People with epilepsy often have difficulty obtaining jobs, and may be dismissed unfairly if they have a seizure at work. The NZLAE intends to work with the lay group, 'Epilepsy New Zealand' to help raise the profile of epilepsy within the general community. People within the broader community need to be more confident in dealing with a person having an epileptic seizure.

At present, many people are frightened when they witness an epileptic seizure, but we believe that this is primarily because of ignorance about epilepsy. We think that information on management of seizures should be given to all children in schools, so that the stigma sometimes associated with the condition can be reduced.

Access to new anti-epileptic drugs

Although many patients with epilepsy have their seizures controlled relatively easily, there are other patients whose seizures are refractory to anti-epileptic drugs. In these situations, it is helpful to have as many options as possible for treating patients. Several drugs have been introduced to neurological practice elsewhere that are not currently available in New Zealand. Foremost amongst these is levetiracetam, which is now widely used throughout Europe, USA, and Australia. It has not yet been introduced to New Zealand, for reasons that are not entirely clear to us.

The New Zealand chapter intends to work constructively with both the drug company and the Pharmaceutical Management Agency of New Zealand (PHARMAC) to ensure that this valuable drug is made available as soon as possible for New Zealand patients.

Research

The New Zealand chapter intends to foster and promote research into various aspects of epilepsy. Research projects currently being undertaken by members of the NZLAE include an Internet recruitment and therapy study and an epilepsy genetics study designed to find new epilepsy genes.

We are keen to explore the use of the Internet to recruit patients for epilepsy drug trials. Although there are now numerous drugs available to treat patients with epilepsy, there is surprisingly little information regarding the optimal treatment of patients with particular epilepsy syndromes. We have therefore created a database and website to collect information about patients' seizure types and epilepsy syndromes, and will encourage neurologists to enter data on patients whose epilepsy is not easily controlled.

We have recently commenced a pilot study in which we are recruiting patients who have failed to respond to the first anti-epileptic drug they were prescribed. Patients will be randomised to receive an alternative anti-epileptic drug. We would like to recruit patients from throughout the country over the next 6 months, and invite physicians, paediatricians, and general practitioners to refer such patients to a neurologist or paediatric neurologist during this period.

The primary focus of this pilot study is to test the process of recruitment and data collection using the Internet. If we can demonstrate that research can be readily conducted in this manner, we will collaborate with epilepsy specialists in other parts of the world to run a series of studies looking at the optimal management of different epilepsy syndromes. Readers interested in further information about this approach to epilepsy trials are referred to our recently published paper.⁶

A significant proportion of the epilepsies are inherited and due to genetic factors.⁷ The objectives of the epilepsy genetic study are to describe the clinical features and genetics of epilepsies found in families, and to identify genes for these epilepsies. Children with epilepsy who have other members in their wider family with epilepsy, and children with rare epilepsy syndromes will be recruited. These individuals and their family members will be interviewed, a family tree will be constructed and blood will be taken for genetic studies.

Each family will have their epilepsy characterised in detail, which in some cases may result in new epilepsy syndromes being identified. Where it is possible to find a causative gene in the family, collaborators will perform molecular genetic analysis. Finding new epilepsy syndromes and the genes responsible for these syndromes will allow more accurate diagnosis and prognosis, and will hopefully lead to novel, improved therapies.

A task force to promote research in epilepsy in the Asia-Oceania region was recently formed, and the New Zealand chapter is now represented in this body. The inaugural meeting of the task force was held at the 27th International Epilepsy Congress, and the president of the New Zealand chapter attended this meeting.

There is great enthusiasm from all member countries of the Asia-Oceania group to perform collaborative studies. It was pointed out at this gathering that 80% of the world's population live in this region, and relatively little study into epilepsy has been performed here.

Guidelines for the management of epilepsy

We intend to promote evidence-based guidelines to ensure that New Zealand doctors give optimal treatment to their patients with epilepsy. There are several areas regarding the management of epilepsy in which new information is coming to light.

Foremost amongst these is evidence that is accruing from various international prospective pregnancy registers.⁸

The New Zealand chapter of the ILAE intends to publicise this material and promote guidelines to minimise the risk of an adverse outcome to both the mothers and children. Similarly, there are other areas such as the management of bone disease in patients with epilepsy where guidelines may be helpful.

We intend to produce guidelines on the management of status epilepticus, so that treatment can be standardised throughout the country. There is evidence that the use of buccal midazolam can be effective as a rescue treatment for some patients with epilepsy,⁹ and we intend to educate health professionals that this as an alternative to rectal diazepam as emergency treatment for patients with severe epilepsy.

We are delighted that PHARMAC has recently made a decision to fund midazolam ampoules for use in the community.

Competing interests: None known.

Note: Any health professional that has a particular interest in epilepsy would be welcome to contact the President, Dr Peter Bergin (pbergin@adhb.govt.nz), or the secretary, Dr Elizabeth Walker (ewalker@adhb.govt.nz).

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