

EPILEPSY ASSOCIATION OF NEW ZEALAND INC.

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Registered Charity: CCI0611



EPILEPSY NEW ZEALAND®
THE NATIONAL EPILEPSY ASSOCIATION OF NEW ZEALAND
kia titiro ki te tangata - see the person

MEDIA INFORMATION

- Please refer to people with epilepsy as ‘people living with epilepsy’ and not as “Epileptic”.
- Epilepsy Association of New Zealand Inc. is a **National** organisation based in Hamilton operating **12 offices** nationwide employing **15 professional Educators**.
- Our revenue relies on community support so as to deliver services. A \$390,000 DIAS contract is held with DHB’s, lead by Waikato DHB, making around 25% of income. Around 93% of income is directly spent on services to people living with epilepsy. Epilepsy Association of New Zealand financial results are available from www.epilepsy.org.nz and Charities Services website.

About epilepsy

Epilepsy is one of the most common neurological conditions that affect many people together with their families, friends and wider networks such as school, workplaces and community groups.

It is a condition characterised by recurrent (two or more) seizures which may have no identifiable cause. An epileptic seizure is a clinical event due to abnormal and excessive discharge of a set of neurons in the brain.

Anyone at any age, intelligence level, ethnic or socioeconomic group can get epilepsy at any time. Epilepsy ranks forth to Migraine, Stroke and Alzheimers disease in the prevalence of neurological disorders, estimated to affect over 50 million people worldwide.

Epilepsy affects more people than autism, amyotrophic lateral sclerosis, curable palsy, multiple sclerosis and Parkinson disease combined¹.

The prevalence rate of epilepsy in NZ is around 1% of the population (**45,000 people**) and the insistent rate is around 0.05% (**6 people per day** compared to Breast Cancer 8 people per day) being diagnosed². We know from international research that around 30%³ of people with epilepsy do not have seizure control even with the best available medicines⁴.

¹ French. J, Kimford. M. (July 2015) Risks of Epilepsy during Pregnancy: How Much Do we Really Know? American Medical Association. USA

² MOH (2012) National Services Service Review Complex Epilepsy Services

³ Mariangela Panebianco, Kalpana Sridharan, Sridharan Ramaratnam (May 2015). Yoga for epilepsy. The Cochrane Collaboration. Published by John Wiley & Sons, Ltd.

*“Epilepsy is a disorder in which recurrent seizures are caused by abnormal electrical discharges in the brain. Most seizures can be controlled by antiepileptic drugs but sometimes seizures develop which are resistant to those drugs. People may also wish to try non-drug treatments such as yoga. **Between 25% and 40% of people with epilepsy treated with AED have uncontrolled seizure, experience adverse effect from medication, suffer from stigmatisation and have a higher degree of psychiatric disorders as compared with people with other chronic illnesses**”.*

⁴ MOH (2012) National Services Service Review Complex Epilepsy Services

People living with epilepsy may suffer significant deficits of their memory, mood disorders, behaviour, judgement and biochemical abnormalities in the brain.

Epilepsy often affects people before or during their most productive years of their life, and complex drug resistant Epilepsy can severely incapacitate and disable.

Epilepsy is considered a chronic lifelong condition but manageable with the potential for multiple co-morbidities.

Overview of international prevalence data applied to New Zealand situation include:

- Prevalence tends to increase with age.
- It is more common in non-European populations.
- By 75 years of age, three per cent of the population can be expected to have been diagnosed with epilepsy and ten per cent will have experienced some type of seizure
- Incidence is highest under the age of 2 and over 65.
- Males are slightly more likely to develop epilepsy than females.
- The incidence is greater in socially disadvantaged communities.
- 70% of people with epilepsy can be expected to be seizure free, (defined as 5 or more years seizure free on medication).
- In patients with complex drug resistant epilepsy, sudden unexpected death may account for as much as 25-65% of all deaths.

Geographic Breakdown of NZ Estimated Prevalence and Incidence Rates- 2014

Area	Population 2014	Prevalence	Incidence	Area	Population 2014	Prevalence	Incidence
Total NZ by DHB/DHB constituency	4509700	45097	2255				
Northland	166000	1660	83	Midcentral	170300	1703	85
Waitemata	562600	5626	281	Whanganui	62200	622	31
Auckland	471900	4719	236	Hutt	143400	1434	72
Counties Manukau	509200	5092	255	Capital and Coast	296700	2967	148
Waikato	383500	3835	192	Wairarapa	42800	428	21
Lakes	103600	1036	52	Nelson Marlborough	143100	1431	72
Bay of Plenty	217400	2174	109	West Coast	32800	328	16
Tairāwhiti	47100	471	24	Canterbury	514500	5145	257
Taranaki	115000	1150	58	South Canterbury	58100	581	29
Hawke's Bay	159400	1594	80	Southern	309900	3099	155

International Mortality Rates

The type of epilepsy suffered; the degree of seizure control, the range and mix of co-morbidities including other neurological damage all contribute to an increased mortality rate for people with

epilepsy. This rate is believed to be 2-3 times greater than that in the general population. People with complex drug resistant epilepsy, have even greater risk, than experienced in the general population. SUDEP may account for 7-17% of deaths in patients with epilepsy.

Social Cost of Epilepsy

Poorly controlled Epilepsy and complex Epilepsy has a significant impact on the person’s quality of life, and lifespan and has high non health care related costs for the country.

Issues of employment, transport, education, housing and social issues of depression and isolation are predominant. Patients with uncontrolled epilepsy often have fewer secondary school qualifications, reduced occupational function and impaired social relationships. They are also likely to have reduced levels of independence due to inability to hold a drivers licence and increased reliance on others for support in daily living conditions. Patients are more likely to have co morbid conditions particularly depression and anxiety, and physical conditions.

Epilepsy is a hidden condition where people don’t want to talk about it because of historic bias, discrimination and stigma that sometimes still exists today.

The individual, social and economic consequences of Epilepsy in New Zealand are unknown. It is internationally acknowledged that non health care costs such as the indirect cost of employment, benefit dependence or premature death likely to be high. A 1992 Australian study showed direct costs was more than AU\$238M pa with indirect costs of AU\$207.2M. An American study suggests that 44% of patients are likely to be unemployed and in receipt of state support⁵ which reinforces ENZ own survey results of 46%.

Epilepsy is a chronic lifelong condition that can be effectively managed to reduce severity and avoid complications. The objective of care is to obtain optimum lifestyle with the parameters of what’s possible given individual condition. The focus of medical care is upon reduction of frequency and severity of seizures and managing the impact of co morbidities.

Symbols

	<p>In registering its ‘Candle Flame’ logo, Epilepsy Association has registered the names ‘Epilepsy New Zealand ®’ and ‘The National Epilepsy Association of New Zealand ®’.</p>
	<p>The Purple Ribbon (™) represents epilepsy awareness. The ribbon has been recently trademarked to remove confusion over its use such as Age Concern, Endometriosis NZ, Chron’s & Colitis NZ and Cancer</p>
	<p>International Epilepsy Day™ is second Monday in February. It is a global campaign designed to raise awareness of Epilepsy.</p>

⁵ Ditto

About Epilepsy Association of New Zealand Inc.

Epilepsy Association of New Zealand Inc. is a National organisation based in Hamilton operating 12 offices nationwide employing 15 x professional Educators to provide local services.

Trading as:	<ul style="list-style-type: none"> The National Epilepsy Association of New Zealand™ Epilepsy New Zealand™ 				
Established	1956				
Nature of Business	Epilepsy New Zealand exists to improve the social condition and quality of life of people with epilepsy, and those who care for them, along with increasing the knowledge of epilepsy in the wider community throughout New Zealand.				
Contact Details	Epilepsy House, 6 Vialou St., PO Box 1074, Waikato Mail Centre, Hamilton 3204. NZ Tel: +64 7 834 3556 Email: national@epilepsy.org.nz Website: www.epilepsy.org.nz				
Vision	<i>To achieve a positive quality of life for all those living with epilepsy in New Zealand</i>				
Mission	<ol style="list-style-type: none"> <i>Promote individual support and interests of PWE so as to achieve self management and positive quality of life.</i> <i>Produce the highest quality information on epilepsy, delivering relevant education & training.</i> <i>Actively raise awareness of living with epilepsy within communities and at all levels of government</i> <i>Commission and promote specialist research into medical and social aspects of epilepsy</i> <i>Actively advocate for people with epilepsy to achieve national outcomes.</i> 				
Charity Registration	CC 10611	Incorporation Number	216663	IRD Number	041-467-924
Board Members:	<p>Paul Kellett (President), IT Specialist 8 Ravenstone Place, Chatswood, Auckland 0626. M: 021 385 276</p> <p>Dr Peter Bergin (Vice President), Neurologist 216 Mt Albert Rd., Sandringham, Auckland 1025. M: 021 480 920</p> <p>Alison Nation (Treasurer), Accountant 79 Pencarrow Rd., Tamahere, RD3, Hamilton 3283. M: 027 284 2236</p> <p>Susan Hill, Executive 5A Beach Road, Mellons Bay, Howick, Auckland 2014. M: 021 998 664</p> <p>Glenys Steele, Employment Lawyer 37 Cashmere Place, Flagstaff, Hamilton 3210 M: 027 699 6953</p> <p>Noel Hensman, Business Manager 82 Weatherly Road, Torbay, Auckland 0630 M: 021 223 7770</p>				
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Bank	BNZ Victoria St., Hamilton. Account: 02 0316 032384 00				
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