

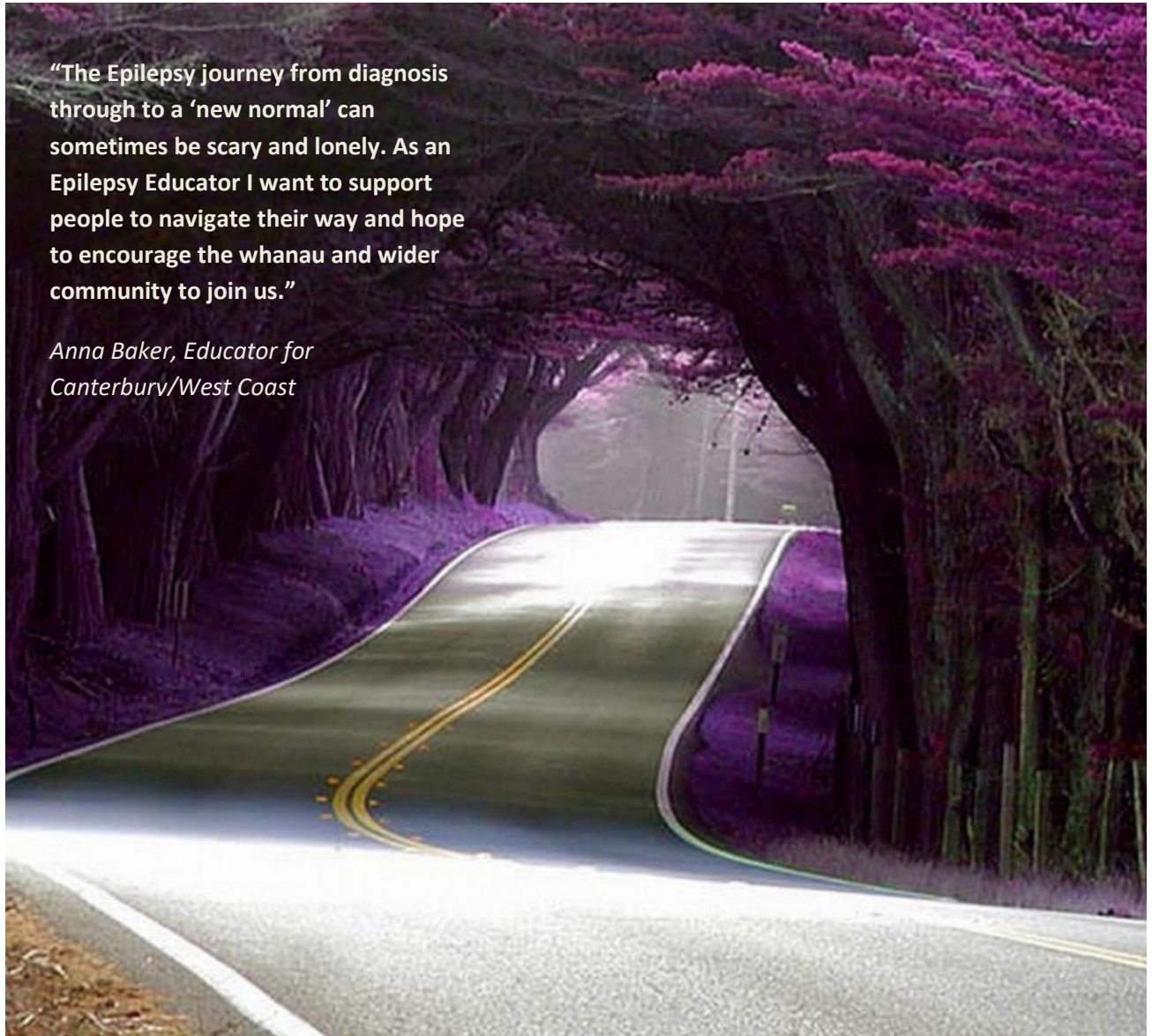
Annual Report 2020

Epilepsy Association of New Zealand Incorporated



"The Epilepsy journey from diagnosis through to a 'new normal' can sometimes be scary and lonely. As an Epilepsy Educator I want to support people to navigate their way and hope to encourage the whanau and wider community to join us."

Anna Baker, Educator for Canterbury/West Coast



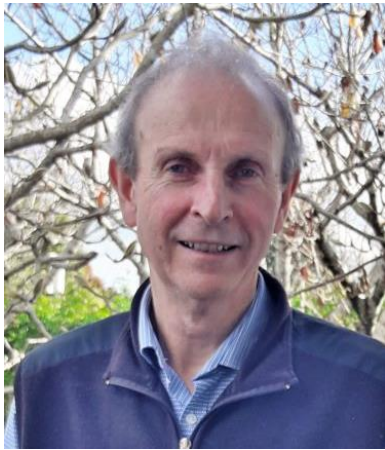
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A huge thank you to all our funders!



President's Report



It has been a very unusual year.

As well as all the usual issues that people with epilepsy have had to deal with over the past year, there have been two extraordinary issues which have arisen.

Covid 19

It is hard to believe that it is only six months since we first heard of Covid-19. For much of this year, we seem to have heard of little else. Fortunately, people with epilepsy have not been at any greater risk of catching this illness than others in the population. In addition, if people with epilepsy have contracted Covid-19, the illness has not been more severe than in other people, and the seizure control does not seem to have deteriorated. Recent studies also suggest that having Covid-19 does not increase the risk of a person developing epilepsy. This is obviously all very reassuring.

The lockdown did affect the way in which ENZ was able to provide services. Our staff have traditionally provided most of our services in a face-to-face way with the clients and staff meeting at the same physical venue. However, this was not possible during the lockdown, and staff rapidly took to providing services via the phone or over the Internet. The feedback that the board has received is that this forced change worked quite effectively, so we are grateful to the educators for their on-going commitment to help people with epilepsy.

Much of ENZ's income comes from charitable trusts and other community organisations, and some of this dried up very abruptly when Covid-19 appeared. Fortunately, we were able to get the Government subsidy during the Stage 4 lockdown period. However, because of the considerable financial uncertainty, we asked all staff to reduce their hours and income by 20%. We are grateful that they were all prepared to do this.

Lamotrigine

In the latter part of 2019, there was considerable concern regarding the decision that Pharmac had made to fund only a single brand of lamotrigine (Logem). Lamotrigine is an excellent anti-seizure medication that is widely used in New Zealand (and internationally) because it is effective against many seizure types and is usually well tolerated. It was estimated that about 10,000 people were taking this drug in New Zealand. Pharmac argued that different brands of lamotrigine were inter-changeable, and that the country could save money by only funding the cheapest brand. However, many people with epilepsy, and the staff and board of ENZ were concerned that people with epilepsy who were stable on their current brand of lamotrigine were being put at some risk by being forced to change brands.

The major difficulty was that no-one really knew how great this risk was; theoretically, the risk should be very low, since generic brands have to be shown to be equivalent to the original product before they can be registered in New Zealand. However, there were many anecdotal reports of people whose seizure-control deteriorated once they changed brands, or they developed new side effects. The NZTA advised that people with epilepsy who were driving (because they had had no seizures for at least a year) should stop driving for a period; this seemed inconsistent with the advice that there was no increased risk. There have also been reports of several patients who died apparently a short time after they changed the brand of their lamotrigine. The upshot of all the debate was that Pharmac backtracked

somewhat and allowed people to stay on their original brand of lamotrigine if their seizure-control deteriorated, if they developed troubling side-effects, or they were unduly anxious about the change. Several thousand people have therefore been able to revert to their original brand (or stay on it.)

The staff and board of ENZ were concerned that there was not sufficient evidence that the approved brand of lamotrigine was actually as good as the Lamictal brand. We were concerned about the reports of people developing new side effects and experiencing an increase in seizures, and even more so about the reports of deaths. We thought it was completely unfair that people with epilepsy should have to stop driving when they were driving safely and legally because NZTA did not share the views of Pharmac that the brands were equivalent.

However, by far our biggest concern was that people with epilepsy would stop their lamotrigine completely because they thought it was in some way dangerous. This would have been a terrible outcome, as it would have meant that people would start having more seizures with an associated risk of injury, status epilepticus and sudden death. For this reason, we tried to reassure people that most people would be able to change brands without any problems, and indeed, this has proved to be the case. At the same time, we tried to work with Pharmac, the NZTA, and other government agencies to get the policy changed.

The outcome here has not been perfect, and many people with epilepsy and their families have been subjected to enormous stress and uncertainty. However, ENZ was trying to walk a fine line, and we think the current compromise is a much better outcome for everyone than what was originally proposed. We hope that Pharmac will undertake wider consultation, and take issues other than financial ones into consideration, before proposing any other changes to funding of anti-seizure medicines.

Thanks

The board would like to thank the educators who have continued providing an excellent service for people with epilepsy. We would also like to thank the staff at the National office, including our very hard-working CEO, Ross Smith.

We would also like to thank our commissioners, David Thorpe and Michael Chapman. Michael has been a commissioner for a number of years, and he has retired from the role this year. We thank him for all the work he has done for people with epilepsy, and we wish him and his family all the best for the future.

I would also like to thank the other Board members who have all been prepared to give up many hours each month to help people with epilepsy.

Finally, special thanks go to all our funders, financial supporters, members and volunteers.

Dr Peter Bergin - President, Epilepsy New Zealand

Chief Executive's Report



Epilepsy New Zealand has a vital role to support people with epilepsy so they can live their best lives. We also work hard to raise awareness of epilepsy and ensure our clients are treated fairly and with respect. During the last year, epilepsy had unprecedented exposure in mainstream media over PHARMAC's badly handled lamotrigine brand switch issue and the seven deaths which have potentially been linked to this.

On your behalf we held PHARMAC and LTSA to account for the confusion and uncertainty they had created for all people with epilepsy and especially those who were normally seizure free and driving. The pressure exerted by us and the entire epilepsy community eventually saw PHARMAC back down and all people given continued access to their preferred brand of lamotrigine.

It's been a tough year financially and the small surplus Epilepsy New Zealand made resulted largely from carrying staff vacancies. COVID-19 had some effect on 2019/20 but will have a major impact on funding in the year ahead. We also learnt a lot during lockdown about operating 'virtually' to support our clients.

The vacancies, particularly in Otago and Wellington and Nelson/Marlborough put additional stress on staff who are covering these areas. I want to acknowledge the impact on people living in these areas and the reduced level of service you may have experienced.

I also want to thank all our staff for their efforts during the year and acknowledge all they achieved -

- 15,700 client contacts;
- 850 seminars held;
- Attended by 6400 people;
- We dealt with over 30,000 information requests and
- Added 554 new clients.

I am constantly reminded however that the true value of our service is not measured by the numbers but whether we made a difference in the lives of the people who trust us with their stories and their lived experience of epilepsy. Some of these stories are in the 'Year in review' section of this report.

Following the decision made at last year's AGM to offer free membership to clients, we have added 88 new client members. While this has a small financial impact on the organisation this is outweighed by having a greater consumer voice within the organisation. While we absolutely value our members, our priority is supporting our entire epilepsy community.

The strength and skill diversity of your Board came to light during COVID-19 and I want to acknowledge their clear and decisive decision-making and strategic focus they provided for me and Epilepsy New Zealand.

It has been a pleasure to serve as your CEO. I welcome contact from all members and our community on any issue. Please don't hesitate to contact me or, if you are in Hamilton call in for a coffee.

Ross Smith – CEO, Epilepsy New Zealand

Treasurers report

I am pleased to report on the consolidated financial results for Epilepsy New Zealand for the year ended 31 March 2020. These accounts carry an unconditional, independent audit certificate.

During the year, The Epilepsy Trust investments were sold and the trust de-registered. The previously unrealised gains on those investments have now been realised and this is reflected in the reported profit this year.

As a controlled entity of the Epilepsy Association, the trust's profit is consolidated into the reported results of the association. The funds, which were transferred to Epilepsy New Zealand have been reinvested.

It is pleasing to note that Epilepsy New Zealand made a small profit through its own efforts for the 2019/20 year.

I would like to thank the Financial Committee for their work this year and Alison Nation in particular for the institutional memory she brings to the meetings. My thanks also to Ross Smith (CEO) and Anneleen Duvenage (Accounts Administrator) for their diligence and careful management of our funding. Although small in number the National office team utilise many of the same accounting systems and processes you would expect find in larger organisations.

Finally thank you to our accountants PKF for their guidance and oversight during the year and Owen McLeod, our auditors for their confirmation of the reported results.

Isabelle Delmotte - Treasurer, Epilepsy New Zealand

Message from our Patron

Sir Bill English became our patron in December 2018.



The work of Epilepsy New Zealand is vitally important because for many families they are the understanding, supportive group in a health system where there can be low visibility.

Epilepsy New Zealand staff share their knowledge and experience, and help those with epilepsy understand better how to manage their lives. This important work can reduce anxiety and improve the lives of so many people.

Epilepsy is a hidden challenge for thousands of New Zealanders. The onset of epilepsy is almost always unexpected, and individuals and families have to learn to live with the risks and uncertainty the disease brings their lives.

To the funders and people all across NZ who financially support the work we do, thank you. You help us make a real difference!

Sir Bill English – Patron, Epilepsy New Zealand

Governance

Board

The Epilepsy Association of New Zealand Incorporated (ENZ) is governed by a Board, responsible for the overall corporate governance and direction of ENZ business and affairs on behalf of members. Board members are elected under the procedures set out in the ENZ constitution. The board elects from its number the President, Vice-President and Treasurer. The President carries out a leadership role in the conduct of the board and its relations with members and other stakeholders. Day-to-day leadership and management of ENZ rest with the Chief Executive Officer, who maintains a close working relationship with the president.

Commissioners

The Commissioners undertake the role of ensuring independence in processing of complaints in relation to decisions of the Board, appeals against membership termination, eligibility of remits to the Annual General Meeting, Board nominations and proposals to award Life Membership.

In May this year Michael Chapman stood down as Commissioner and Letticia Mincham was appointed as Commissioner through to the AGM.

Epilepsy Trust

In line with the resolution passed in July 2019, The Epilepsy Trust has been deregistered and its realised investments transferred to Epilepsy New Zealand. The Board has commenced a reinvestment programme to ensure these funds remain safe and continue to produce investment income.

The Board would like to acknowledge the excellent stewardship provided by The Epilepsy Trust board: Paul Kellett (Chair), Brian Jonasson, Michael Chapman and David Vickery.

About Epilepsy Association of New Zealand Inc.



Epilepsy Association of New Zealand Inc. is a member of the International Bureau of Epilepsy (IBE). The Association is a nationwide organisation based in Hamilton, with Educators located throughout New Zealand to deliver local services including information, education, support and community awareness.

Trading as:	The National Epilepsy Association of New Zealand™ Epilepsy New Zealand™				
Established	1956				
Nature of Business	<p>Epilepsy New Zealand exists to improve the social condition and quality of life for people with epilepsy, and those who care for them, along with increasing the knowledge of epilepsy in the wider community throughout New Zealand.</p> <p>Community-based epilepsy educators work with clients across NZ supported by a national support centre in Hamilton.</p>				
Contact Details	<p>Epilepsy House, 6 Vialou St., PO Box 1074, Hamilton 3204. New Zealand. Tel: 07 834 3556 Email: national@epilepsy.org.nz Website: www.epilepsy.org.nz</p>				
Vision:	A New Zealand that is free of discrimination and stigma, where the impacts of epilepsy on a person's life, and that of their whanau and community, are minimised.				
Mission:	To improve the quality of lives of New Zealanders living with Epilepsy				
Values:	Leadership, Inclusive, Empowering, Integrity, Sustainable, Professional, Responsible, Transparent				
Charity Registration	CC 10611	Incorporation Number	216663	IRD Number	041-467-924
Patron	Sir Bill English				
Volunteer Board Members:	<p>Dr Peter Bergin – President Renee Wood - Vice President Dr Isabelle Delmotte –Treasurer Philippa Tolley Matt Paterson Lucy Acott Ricky Bennett</p>				
Volunteer Commissioners	<p>Michael Chapman (up to 27 May 2020) David Thorp</p>				
Management	<p>CEO Ross Smith (appointed August 2019) Email: ceo@epilepsy.org.nz</p>				
Bank	BNZ Victoria St., Hamilton. Account: 02 0316 032384 00				
Accountants	PKF Hamilton, Chartered Accountants, 1026 Victoria St., Hamilton 3204 T: 07 839 2106				
Auditors	Owen McLeod , 91 Clarence St, Hamilton Lake, Hamilton West 3204 T: 07 839 1235				

Year in review

Membership

Although membership is down on last year, there are some pleasing trends. During lockdown we asked the educators to promote the free 'client memberships' which resulted in 88 people joining Epilepsy New Zealand.

A number of organisations like ours, have faced similar levels of declining membership and moved away from the incorporated society model. I believe this is a debate we should have in the next 1-2 years as the influence we have is increasingly shifting to a virtual, online and social media presence.

There is an increasing trend in society for people to turn away from the more formal structures of club and society membership towards a less rigid, rules-based 'following' online. Epilepsy New Zealand has almost 6500 followers on our FaceBook page and this is only one of the many pages people with epilepsy turn to for help and advice. In order to remain relevant to the next generation, it is important we communicate in ways they resonate with.

"I am amazed at the outpouring of support on FaceBook - It is not uncommon for a question online to receive dozens of genuinely helpful replies within half an hour of posting" (client)

About our services

Epilepsy can affect any person at any time therefore the people who seek our services vary widely and can be any age, at any stage of life, with individual needs, unique problems plus their own hopes, aspirations and personal goals for their future.

Providing quality, relevant and valued client services that make a difference to people's lives and their journey with epilepsy is at the heart of what we do.

Our services essentially can be described as provision of:

- Individual support
- Education and Training
- Public Awareness & Advocacy
- Information requests

Individual Support

- No of client contacts – 15,752

Providing individual support is about meeting people where they are and stepping into their reality. No-one does this better in Northland than our educator Sam (Ngati.....)

Off the tar seal and down the corrugated metal roads. I am greeted with, 'so whaea?' Where are you from?

Following a recent visit to a remote area in the far North, I am constantly reminded of the importance of whakawhangaungatanga - the connections and quality of relationships amongst whanau, hapu, iwi and the wider community.

I often think how privileged I am as an Epilepsy New Zealand educator to be invited into a whare/home; to meet the person with epilepsy, tangata and their whanau in their own home environment.

To listen, to share and to empower tangata/whanau with epilepsy knowledge and understanding and to observe the enlightenment of what this new knowledge does is so powerful.

As a result, there is often a request for further extended whanau or community hui.

Working with a holistic approach is paramount in addressing the wider impact that epilepsy can have on whanau, extended whanau friends and the wider community. Using the expert resources made available through the organisation is important. Whanau need to know the facts and the science too.

Equally important is acknowledging the strengths of tangata/whanau in addressing the needs of the person with epilepsy. This may include a conversation around wairua (spiritual) often initiated by whanau and what it means to them.

Wairua, has a depth and meaning to the person with epilepsy and their whanau. It is the very essence of wellbeing. Out of their wairua they get a sense of perspective and balance to any learned knowledge and understanding of epilepsy.

Welcome to my world - this is remote, coastal Northland where our largest percentage of rural Maori and European families live and who acknowledge and appreciate the travel and support offered by Epilepsy New Zealand to their area.

There's a saying 'if you've met one person with epilepsy, you've met one person with epilepsy'. The next story from educator Anna-Lee illustrates the complexity of providing individual support to clients and how we never know what direction our service will take.

What started as a routine request for a total mobility taxi card, identified the impact this mother's epilepsy was having on her young pre-teen daughter.

Dealing with her own increasing number of weekly seizures was a major for this Mum but her main concerns were more around her young pre-teen daughter who was taking responsibility for looking after her Mum; she was on edge listening out to her Mum for sounds, feeling anxious and also recently been feeling very resentful and angry with some behavioural issues.

An unexpected seizure while out shopping when no-one came to offer assistance was upsetting to both mother and daughter and a reminder of the stigma and discrimination many people with epilepsy live with constantly.

We discussed some things that I would look into for both of them:

- *Simplifying a safety plan. We printed and laminated a note for the mother's phone so the daughter could show people if needed.*
- *Epilepsy education with myself for daughter scheduled.*
- *We investigated respite and other programmes though the cost was a potential barrier to access.*
- *GP gave Child Health referral, as well to a counselling service should they wish to go to.*
- *We investigated what other resources from community mental health providers may have been available for children.*
- *The opportunity to meet with other children/a group of people who have parents with epilepsy.*
- *We provided epilepsy/seizure children's videos for the daughter.*
- *St John membership- they are looking at joining and already have brochure.*
- *Medic Alert and GPSOS seizure alarms were discussed and brochures provided*
- *Other resources provided to the daughter included Youthline brochure, a comic book explaining epilepsy, recognition and first aid information sheet, first aid posters.*

I feel like this entire family is my client. I let them know any of them can contact me if they have any queries or would like to talk. I also have their contact details with their consent.

My client and her family thanked me, by having education on the seizures and epilepsy they felt they had more of an understanding of the different seizures and first aid management. This also gave them more confidence to go out and do the activities that they enjoy in the community.

It also really helped them to be able to talk in a comfortable, trustworthy and safe environment.

Education and training

- Seminars held - 851
- Seminar attendance – 6,389

Our seminars take many forms from family meetings to meetings with school staff to assisting our clients with issues in their workplace.

Our educators are passionate about helping children have a normal educational experience and to build healthy school environments where the condition is destigmatised and staff are ready and equipped with first aid training and other supports they need.

Anna is one of our educators and being an ex-teacher has a special affinity for her school work. She shares these stories.

A school in my region had a child with quite complex epilepsy; although we were unable to visit the school, we were able to support them online. We were able to run an interactive Zoom session where the educator and staff were able to communicate; videos were shared, questions were asked and general guidance and support was given.

Afterwards the response from staff was positive with an email thanking me for the session saying “Thank you so very much for the training, staff couldn't stop mentioning how great it was and how helpful; they honestly were raving about how much they learnt and how helpful you were.”

In another school I supported both staff and children at the school. During the day I ran two fun interactive brain health and epilepsy awareness programmes for both the junior and senior children.

Staff felt the session boosted the moral of the child with epilepsy and gave her a better sense of identity sending me an email saying “It was absolutely wonderful and just what we needed! Her teacher told me that she was like a different child yesterday and we are thinking that perhaps it is because she feels like everyone understands her now.”

Public awareness and advocacy

- Information requests – 30,213
- New clients added - 534

When we advocate for someone we go ‘the extra mile’ for them. Sometime we encounter a reluctance to engage and this story from educator Jenny, speaks to the tenacious spirit she brings to her role.

I received a referral for a young man whom was rather reluctant to meet with me and initially declined contact. I knew some of the issues surrounding the referral so worked hard to negotiate a time to deliver a brochure about Epilepsy New Zealand and our service. In the course of conversation with delivery it became obvious this young man was anxious and in a difficult place having been involved in an accident,

lost his job, had no income and was feeling unsupported in his home environment due to his epilepsy being misunderstood both by himself and family.

At the initial visit we agreed to talk to his family and explain his condition and how they could best support him. That was the start of a process that eventually saw him regain some confidence and help to navigate the supports he needed in the community.

We keep in contact and I visited again and we talked about his plans to get his life on track and options to look at in the future.

When we last spoke, he was flatting with great flat mates and had secured a job. But more importantly he felt secure, happy and was confident with his knowledge and understanding of his epilepsy and his management.

I could feel his trust in our service and I know if we are needed in the future this will happen.

I have had many more referrals this year that if not for the opportunity to visit I would not have been invited in to share the barriers and complexity of the needs that many people are facing.

It is clear it is often not enough to provide information alone. What is needed is to have a relationship and information. These together have the most beneficial impact for our client's health and wellbeing.

I am proud that we at Epilepsy New Zealand we are able to provide this service with our visits to clients. Whakawhanaungatanga - a valued resource.

Ross Smith – CEO, Epilepsy New Zealand

Strategic Plan

Our new strategic plan framework.

Epilepsy New Zealand Strategic Plan 2020 - 2025



Mission: To improve the quality of lives of New Zealanders living with Epilepsy

Sustainably through

Personalised Support

Taunakitanga motuhake

- Information and assistance for everyone living with epilepsy, and their families/whanau
- Help for people to become empowered and gain optimal control of their seizures
- Targeted programmes for each stage of life

Awareness

Moohiotanga

- Increase recognition and understanding of epilepsy in all communities, including Maori and Pasifika
- Reduce fear
- Strengthen relationships with key partners

National Voice for Change

Maangai

- Represent and advocate for the rights of those with epilepsy including
 - Government & governmental agencies
 - The health & disability sector
 - The education and employment sector
 - In research

Education & Training

Akoranga

- People with epilepsy
- Families
- Schools
- Workplaces
- Health Professionals
- Aged Care
- Community Groups
- Public facilities
- Government agencies

Our Values

Leadership, Inclusive, Empowering, Integrity, Sustainable, Professional, Responsible, Transparent
Hautuutanga, Taapiripiri, Whakamana, Mana, Toituu, Manawanui, Tuutika, Maarama(tanga)

Supporters of Epilepsy New Zealand

Key Funders

- **Ministry of Health / District Health Boards**
- **NZ Lottery Grants Board**
- **Pub Charity Limited**

Community Organisation Grants Scheme

Auckland City	Nelson Bays	Taranaki South
Central Otago	Papakura Franklin	Tauranga Moana
Coastal Otago Waitaki	Rodney North Shore	Wairarapa
Hutt Valley	Rotorua	Waitakere
Kahungunu	Southland	Wellington
Tonagariro	Tairāwhiti	Whanganui
Manukau	Tamatea	Whangarei Kaipara
Mataatua	Taranaki North	Whitirea

Councils

Auckland Local Boards Howick	Kawerau District Council
Auckland Local Boards Kaipātiki	Lake Taupo District Council
Christchurch Council	Martinborough Community Board
Dunedin City Council	South Waikato District Council
Kapiti District Council	Upper Hutt City Council

Grants — Community

Bay Trust	Rata Foundation
Central Lakes Trust	Rotorua Community Fund
Christchurch Airport Community Fund	TECT
Disability Community Trust EBOP	Trust Tairāwhiti
Eastern and Central Community Trust	Trust Waikato
Harcourts Foundation	Waikato WDFF Karamu Trust
Kiwanis Club of Tauranga	West Coast Community Trust
Mazda Foundation	Whanganui Community Foundation
NZ Post	

Grants — Gaming

Air Rescue Services	Mt Wellington Foundation
Blue Waters Community Trust	North and South Trust
CERT	Oxford Sports Trust
First Light Community Foundation	Sky City Queenstown
Four Winds	The Trusts Community Foundation
ILT Foundation	Trust House Foundation
Mainland Foundation	The Southern Trust
Milestone Foundation	NZ Charitable Trust
Trillian Trust	

Grants — Philanthropic

AW Parsons Trust
Esme and Tom Tombleson Charitable Trust
George Brown Charitable Trust
Guy Anson Waddel Charitable Trust
Helen Graham Charitable Trust
Hugo Charitable Trust
JBS Dudding Trust
Jack Jeffs Charitable Trust
JN William Memorial Trust
Kathleen Dorothy Kirkby Trust

LW Nelson Charitable Trust
Maurice Paykal Charitable Trust
Nessbank Trust
Page Trust
Roy Owen Dixey Charitable Trust
South Canterbury Trusts
Stewart Family Charitable Trust
W Duncan Bickley Trust
The Epilepsy Foundation

Donors

J A Day
Norman Barry Foundation / Quality Hotel
Christchurch Boy's High
Give-a-little / Spark Foundation
The Johnstone Trust
Brett Stevens Trust Fund

Other donations

Gallagher Group Limited
The Digital Wings Trust

Appendix 1: Financial Report

Annual Report

Epilepsy Association of New Zealand Inc.
For the year ended 31 March 2020

Prepared by PKF Hamilton Limited

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Entity Information

Epilepsy Association of New Zealand Inc. For the year ended 31 March 2020

'Who are we?', 'Why do we exist?'

Legal Name of Entity

Epilepsy Association of New Zealand Inc.

Entity Structure

Epilepsy Association of New Zealand is a registered Not-For-Profit charity, operated by a Board of Trustees. It represents its membership by operating a centralised management structure, located in Hamilton. It presently delivers its services in 10 locations throughout New Zealand, employing 12 professionally trained educators that deliver individualised client education, information and support services together with a localised community awareness and education program.

The Association has the power to do anything lawful that maybe necessary or conducive to attain its objectives exercised by its elected Board, which is aided by elected Commissioners who assist with Board member elections and complaints against the Board. The Board functions include overseeing the conduct of Association business and of appointed CEO to manage the day to day affairs of the Association in accordance with the organisations objectives together with the policy and direction determined by the Board.

Directory

Commissioners

Micheal Chapman

David Thorpe

Board Members

Dr. Peter Bergin (President)

Dr. Isabelle Delmotte (Treasurer)

Susan Hill (Retired from August 2019)

Philippa Tolley

Renee Wood (Vice President)

Matthew Paterson

Lucy Acott (Board Member from October 2019)

Ricky Bennett (Board Member from February 2020)

CEO/Secretary

Graeme Ambler (Resigned from May 2019)

Ross Smith (CEO from August 2019)

Entity Type and Legal Basis

Epilepsy Association of New Zealand (ENZ) is a registered Incorporated society under the Incorporated Societies Act 1908 and Charities Act 2005.



Entity Type and Legal Basis

Epilepsy Association of New Zealand (ENZ) is a registered Incorporated society under the Incorporated Societies Act 1908 and Charities Act 2005.

Registration Number

Incorporation Number 216663

Registered Charity CC10611

Entity's Purpose or Mission

Vision: To positively influence the lives of people with epilepsy, their families and communities.

Mission: To empower people with epilepsy, while eliminating discrimination, by increasing awareness and understanding of epilepsy.

Main Sources of Entity's Cash and Resources

ENZ has a small government contract with all DHB's in New Zealand. NZ Lotteries and other charitable organisations fund day to day activities. ENZ has a heavy reliance upon support from the general public in donations and appeals.

Main Methods Used by Entity to Raise Funds

Donation Events/Campaigns

Entity's Reliance on Volunteers and Donated Goods or Services

Volunteers assist in governance with the majority of events undertaken by volunteers.

Physical Address

6 Vialou Street

Hamilton

Postal Address

PO Box 1074, Waikato Mail Centre

Hamilton

New Zealand



Approval of Performance Report

Epilepsy Association of New Zealand Inc.

For the year ended 31 March 2020

The Trustees are pleased to present the approved performance report including the historical financial statements of Epilepsy Association of New Zealand Inc. for year ended 31 March 2020.

APPROVED



Dr. Peter Bergin

President

Date 16 July 2020



Dr. Isabelle Delmotte

Treasurer

Date16/07/20.....

Statement of Service Performance

Epilepsy Association of New Zealand Inc.

For the year ended 31 March 2020

'What did we do?', 'When did we do it?'

Description of Entity's Outcomes

Epilepsy Association of New Zealand seeks to promote the welfare and interest of people with epilepsy in New Zealand and their family/ whanau through education, information support and public awareness. To deliver services as agreed with District Health Board. To build and maintain a suitable organisation to ensure the Association can continue to provide for people in NZ living with epilepsy.

	2020	2019
Description and Quantification of the Entity's Outputs		
Number of Members	302	341
Number of Clients registered with ENZ	7,403	7,714
Number of Client Contacts	15,752	15,368
Number of Seminars Held	800	838
Number of people attending Seminars	6,389	8,115
Number of Non-client contacts - not registered with ENZ	31,987	36,266
Total Number of people assisted	54,128	59,749

Description and Quantification of the Entity's Outputs

Epilepsy Association of New Zealand provides individual information, education and support to people with epilepsy and their networks so as to achieve better health outcomes through self management and community inclusion. Wider community education and awareness is delivered to a wider variety of places including schools, health professionals and community organisations to increase understanding of epilepsy. Our goal is to increase membership presence in the community and to increase public understanding so as people with epilepsy are included in the community without fear of prejudice and stigma.



Statement of Financial Performance and Comprehensive Income

Epilepsy Association of New Zealand Inc.
For the year ended 31 March 2020

'How was it funded?' and 'What did it cost?'

	NOTES	Group 2020	Group 2019 (RESTATED)
Revenue			
Donations, fundraising and other similar revenue	1	750,742	739,292
Fees, subscriptions and other revenue from members	1	1,609	1,166
Revenue from providing goods or services	1	411,001	408,261
Interest, dividends and other investment revenue	1	15,519	15,766
Other revenue	1	219,395	522
Total Revenue		1,398,268	1,165,007
Expenses			
Expenses related to public fundraising	2	3,949	4,536
Volunteer and employee related costs	2	896,861	980,044
Costs related to providing goods or service	2	160,707	191,137
Other expenses	2	104,354	100,491
Total Expenses		1,165,872	1,276,208
Surplus/(Deficit) for the Year		232,396	(111,201)
Other Comprehensive Income			
Unrealised Gain/(Loss) on Investments		-	30,831
Total Other Comprehensive Income		-	30,831
Total Comprehensive Income for the Year			
Total Comprehensive Income		232,396	(80,370)
Total Total Comprehensive Income for the Year		232,396	(80,370)

This statement should be read in conjunction with the notes to the Performance Report and Statement of accounting policies.



Statement of Financial Position

Epilepsy Association of New Zealand Inc.

As at 31 March 2020

'What the entity owns?' and 'What the entity owes?'

	NOTES	Group 31 MAR 2020	Group MAR 2019 (RESTATED)
Assets			
Current Assets			
Bank accounts and cash	3	691,641	355,896
Debtors and prepayments	3	49,751	49,843
Inventories	3	1,390	1,390
Total Current Assets		742,781	407,129
Non-Current Assets			
Property, Plant and Equipment	5	261,619	274,345
Investments	3	2,489	364,336
Total Non-Current Assets		264,108	638,681
Total Assets		1,006,889	1,045,810
Liabilities			
Current Liabilities			
Creditors and accrued expenses	4	33,346	73,126
Employee Costs Payable	4	108,253	103,721
Unused donations and grants with conditions	9	218,407	307,301
Total Current Liabilities		360,005	484,148
Total Liabilities		360,005	484,148
Total Assets less Total Liabilities (Net Assets)		646,884	561,662
Accumulated Funds			
Accumulated surpluses	6	646,884	414,481
Fair Value Reserves	6	-	147,181
Total Accumulated Funds		646,884	561,662

This statement should be read in conjunction with the Performance Report and Statement of accounting policies.



Statement of Cash Flows

Epilepsy Association of New Zealand Inc. For the year ended 31 March 2020

'How the entity has received and used cash'

	NOTES	Group 2020	Group 2019 (RESTATED)
Cash Flows from Operating Activities			
Donations, fundraising and other similar receipts		661,848	970,613
Fees, subscriptions and other receipts from members		1,609	1,166
Receipts from providing goods or services		410,675	405,828
Interest, dividends and other investment receipts		226,358	15,766
GST		472	24,033
Payments to suppliers and employees		(1,183,127)	(1,260,813)
Cash receipts from other operating activities		3,041	522
Total Cash Flows from Operating Activities		120,875	157,114
Cash Flows from Investing and Financing Activities			
Receipts from sale of property, plant and equipment		15,222	904
Receipts from sale of investments		-	20,000
Payments to acquire property, plant and equipment		(17,448)	(10,848)
Cash Flows from Other Investing and Financing Activities		217,095	-
Total Cash Flows from Investing and Financing Activities		214,869	10,056
Net Increase/(Decrease) in Cash		335,745	167,170
Cash Balances			
Cash and cash equivalents at beginning of period	3	355,896	188,726
Cash and cash equivalents at end of period	3	691,641	355,896
Net change in cash for period		335,745	167,170

This statement should be read in conjunction with the notes to the Performance Report and Statement of accounting policies.



Statement of Accounting Policies

Epilepsy Association of New Zealand Inc.

For the year ended 31 March 2020

'How did we do our accounting?'

Basis of Preparation

The entity has elected to apply PBE SFR-A (NFP) Public Benefit Entity Simple Format Reporting - Accrual (Not-For-Profit) on the basis that it does not have public accountability and has total annual expenses equal to or less than \$2,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. The Performance Report is prepared under the assumption that the entity will continue to operate in the foreseeable future.

These financial statements are group financial statements representing the consolidated financial results and position of Epilepsy Association of New Zealand Inc and its subsidiary the Epilepsy Trust.

Basis of Consolidation

Controlled entities are all those entities over which the controlling entity has the power to govern the financial and operating policies so as to benefit from its activities. The controlled entities are consolidated from the date on which control is transferred and are de-consolidated from the date that control ceases. In preparing the consolidated financial statements, all inter-entity balances and transactions, and unrealised gains and losses arising within the consolidated entity are eliminated in full. The accounting policies of the controlled entity are consistent with the policies adopted by the Group and have a 31 March reporting date.

Goods and Services Tax (GST)

The Association is registered for GST. All amounts are stated exclusive of goods and services tax (GST) except for accounts payable and accounts receivable which are stated inclusive of GST.

Income Tax

The Association and the Trust are registered as a charitable entity under the Charities Act 2005 and is exempt from income tax under the income tax legislation.

Bank Accounts and Cash

Bank accounts and cash are short term, highly liquid investments that are readily convertible to known amounts of cash and which are subject to an insignificant risk of changes in value.

Changes in Accounting Policies

There have been no changes in accounting policies. Policies have been applied on a consistent basis with those of the previous reporting period.

Revenue

Revenue is recognised to the extent that it is probable that the economic benefit will flow to the Group and revenue can be reliably measured. Revenue is measured at the fair value of the consideration received. The following specific recognition criteria must be met before revenue is recognised.

Donation, Fundraising & Other similar revenue

Donations are recognised as revenue upon receipt.

Grant revenue includes grants given by other charitable organisation, government sector and public. Grant revenue is recognised when the conditions attached to the grant has been complied with. Where there are unfulfilled conditions attaching



to the grant, the amount relating to the unfulfilled condition is recognised as a liability and released to income as the conditions are fulfilled.

Revenue from legacies and estates that satisfies the definition of an asset is recognised as revenue when it is probable that future economic benefits or service potential will flow to the entity, and the fair value can be measured reliably.

Revenue from provide goods & services

The Association receives revenue from the central government to provide services to people with epilepsy. Revenue is recognised in the period the goods and services are provided.

Interest Revenue

Interest revenue is recognised as it accrues, using the effective interest method.

Dividend Income

Dividend Income is recognised when the right to receive payment is established.

Property, Plant & Equipment

Property, plant & equipment are stated at cost less accumulated depreciation and impairment losses. Depreciation is provided on a diminishing value basis over the useful life of the asset except for land. Depreciation is charged at rates calculated to allocate the cost of the asset less estimated residual value over it's remaining useful life. Shown below are depreciation rates by the Association

Building	4%
Motor Vehicle	20% - 30%
Furniture & Fittings	12% - 48%
Office Equipment	12% - 40%
Computer Equipment	33% - 50%

Liabilities

Tagged funds related to grants received with a 'use or return' condition. At the reporting date any grants with 'use or return' condition unused are recorded as a liability until these grants are used for the specific purpose or returned to the granting party.

Trade payable and accruals

These amounts represent liabilities for goods and services provided to the association prior to the end of financial year which are unpaid.

Leases

Payment on operating lease agreements, where the lessor retains substantially the risk and rewards of ownership of an asset, are recognised as an expense on a straight-line basis over the lease term.

Investments

The Association has elected to apply the provisions of the Tier 2 PBE accounting standards in place of the requirements of PBE SFR-A (NFP) standards in respect of the measurement of its investments on the basis that it results in the Performance Report providing more relevant information about the Association's financial performance.

In accordance with Tier 2 PBE accounting standards, the Association's investments are classified as available-for-sale financial assets and are therefore initially recorded at fair value (inclusive of directly attributable transaction costs) and subsequently measured at fair value. Any gain or loss in fair value is then recognised in other comprehensive income until the asset is derecognised, at which time the cumulative gain or loss previously recognised in other comprehensive income is reclassified to



profit or loss as a realised gain or loss on derecognition. In the case of the Association's investments, the fair value is based on a market valuation of the investment portfolios as at balance date.

At each balance date, the Association assesses whether there is any objective evidence of impairment. If such evidence exists, any cumulative loss recognised in other comprehensive income in relation to that investment shall be reclassified to profit or loss as an impairment loss.



Notes to the Performance Report

Epilepsy Association of New Zealand Inc.

For the year ended 31 March 2020

	Group 2020	Group 2019
1. Analysis of Revenue		
Donations, fundraising and other similar revenue		
Bequests	50,031	134,306
Community Organisation Grant Scheme (COGS)	54,000	40,036
Donations	88,216	46,105
Donor Appeal	2,472	940
Event Marketing	-	10,061
Grants - Community	176,104	104,911
Grants - Gaming	69,108	163,652
Grants - Philanthropic	81,917	48,587
Lottery National Community	140,000	190,694
Unspent grant income b/fwd from previous year	307,302	-
Unspent grant income c/fwd to next year	(218,407)	-
Total Donations, fundraising and other similar revenue	750,742	739,292
Fees, subscriptions and other revenue from members		
Memberships	1,609	1,166
Total Fees, subscriptions and other revenue from members	1,609	1,166
Revenue from providing goods or services		
Chargeable Income	1,670	5,868
Merchandise Income	208	409
Ministry of Health	407,462	399,718
Mobility Income	235	2,093
Sundry Income	1,427	173
Total Revenue from providing goods or services	411,001	408,261
Interest, dividends and other investment revenue		
Dividends Received	7,918	8,809
Interest Received	7,601	6,933
Investment Income	-	24
Realised Gain/(Loss) On Investments	210,838	-
Total Interest, dividends and other investment revenue	226,357	15,766
Other revenue		
Profit on Sale of Fixed Assets	5,566	-
Rental Income	2,991	522
Total Other revenue	8,558	522
	Group 2020	Group 2019

2. Analysis of Expenses

Expenses related to public fundraising

Advertising & Marketing	3,949	4,013
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	Group 2020	Group 2019
Fundraising Expenses	-	377
Refund of Grants	-	145
Total Expenses related to public fundraising	3,949	4,536
Volunteer and employee related costs		
ACC Levies	2,798	2,640
Car parking - Office	6,398	4,904
Health Insurance	13,311	14,504
Staff Amenities & Cleaning	3,887	3,017
Volunteer Expenses	-	73
Wages & Salaries	870,468	954,906
Total Volunteer and employee related costs	896,861	980,044
Costs related to providing goods or services		
Car Parking - General	870	886
Electricity/Gas	4,857	5,515
Fuel Card	26,985	36,168
Information Resources	24,461	4,906
Meeting Expenses	543	278
Motor Vehicle Expenses	12,255	14,082
Postage,Printing and Stationery	13,571	15,653
Public Awareness	474	1,605
Public Relations	39	23
Rates	987	791
Relationship Expenses	69	216
Rent	37,648	59,667
Staff Development & Training	6,266	6,462
Support Meetings	2,176	2,458
Telecommunications	18,373	26,522
Total Mobility Charges	217	191
Travel & Accommodation	9,141	14,111
Website	1,772	1,602
Total Costs related to providing goods or services	160,707	191,137
Other expenses		
Brokerage Fees Re Closing Funds	1,495	-
Consultants	464	-
Accountancy Fees	14,705	9,925
Affiliation & Subscriptions	1,633	2,210
Audit Fees	13,000	14,270
Bank Fees	2,393	2,436
Board Expenses	6,908	5,895
Charities Commission	44	44
Computer Maintenance	7,632	5,975
Contract Work	9,463	3,500
Depreciation	19,526	18,103
Insurance	15,467	17,695
Interest - Bank Overdraft	618	763
Legal Fees	5,431	11,339
Loss on Sale of Fixed Assets	1,013	2,796



Merchandise	280	-
Office Equipment Under \$500	335	1,768
Outgoings	790	1,423
Repairs & Maintenance	3,158	2,348
Total Other expenses	104,354	100,491

Group
2020

Group
2019
(RESTATED)

3. Analysis of Assets

Bank accounts and cash

CIP Cashman Nominees - Call Account	-	2,461
Epilepsy Trust - 00	-	39,136
Epilepsy Trust - 02	-	23,817
Main Operating Account	263,335	290,481
National Investment	428,305	1
Purple Day	1	-
Total Bank accounts and cash	691,641	355,896

Debtors and prepayments

Prepayments	9,089	10,459
Related Party Receivable - others	2,489	-
Sundry Debtors	40,662	39,384
Total Debtors and prepayments	52,240	49,843

Inventories

Inventory - Information Resource	1,169	1,169
Inventory - Soft Toys	-	-
Inventory - T-Shirts	220	220
Total Inventories	1,390	1,390

Investments

Opening Balance	364,287	353,456
Redemption	-	-
Brokerage Fees	(1,425)	-
Interest Earned	1,059	-
Investments Matured	-	(20,000)
Loss on disposal investment	-	-
Realised Gain/(Loss) on Investments (Current)	63,658	-
Unrealised losses on investment (Current)	-	-
Unrealised gain on investments (Non-current)	-	30,831
Net Settlement Amount	(427,579)	-
Total Investments	-	364,287

Group
2020

Group
2019
(RESTATED)

4. Analysis of Liabilities

Creditors and accrued expenses

GST	30,989	30,509
Accrued Audit Fee	13,000	12,200



	Group 2020	Group 2019
Sundry Creditors	(10,643)	30,417
Total Creditors and accrued expenses	33,346	73,126
Employee costs payable		
Accrued Employee Entitlement	26,601	34,918
Holiday Pay Accrual	42,246	43,716
Wages Deductions Payable	27	-
Wages Payable - Payroll	39,379	25,087
Total Employee costs payable	108,253	103,721
	Group 2020	Group 2019

5. Property, Plant and Equipment

Buildings

Opening Carrying Amount	238,506	245,485
Purchases	-	-
Sales & Disposals	-	-
Current Year Depreciation	(6,700)	(6,979)
Total Buildings	231,806	238,506

Motor Vehicles

Opening Carrying Amount	17,806	25,263
Purchases	15,486	-
Sales/Disposals	(10,567)	(2,130)
Current Year Depreciation	(6,402)	(5,328)
Total Motor Vehicles	16,323	17,805

Furniture and Fittings

Opening Carrying Amount	6,507	5,306
Purchases	-	3,200
Sales/Disposals	(59)	(780)
Current Year Depreciation	(1,056)	(1,219)
Total Furniture and Fittings	5,392	6,507

Office Equipment

Opening Carrying Amount	2,385	4,207
Purchases	-	-
Sales/Disposals	(22)	(783)
Current Year Depreciation	(674)	(1,039)
Total Office Equipment	1,689	2,385

Computer Equipment

Opening Carrying Amount	7,441	2,608
Purchases	1,982	7,648
Sales/Disposals	-	(7)
Current Year Depreciation	(4,205)	(2,808)
Total Computer Equipment	5,218	7,441

Plant and Equipment

Opening Carrying Amount	1,701	2,430
Purchases	-	-
Sales/Disposals	-	-



	Group 2020	Group 2019
Current Year Depreciation	(510)	(729)
Total Plant and Equipment	1,191	1,701
Total Property, Plant and Equipment	261,619	274,345

6. Accumulated Funds

2020 Group	Accumulated Surpluses/(deficits)	Fair Value Reserve	Total
Opening Balance	414,482	147,181	561,662
Capital gain on sale of fixed assets	-	-	-
Surplus/(deficit)	232,396	-	232,396
Fair value gain on Investment	-	(147,181)	(147,181)
Total	646,884	-	646,884

2019 Group (RESTATED)	Accumulated Surpluses/(deficits)	Fair Value Reserve	Total
Opening Balance	525,683	116,349	642,032
Capital gain on sale of fixed assets	-	-	-
Surplus/ (deficit)	(111,201)	-	(111,201)
Fair value gain on Investment	-	30,831	30,831
Total	414,482	147,180	561,662

7. Restatement Investments

Investments in Meridian Energy Ltd shares of \$75,330 (market value in 2019) is overstated. The shares were sold during the 2016 financial year and was incorrectly recorded as investment income in the 2016 financial statements. As a result, opening Accumulated surpluses, Investments and Unrealised Gain/(Loss) on Investments (Non-Current) are overstated.

The 2019 Financial Statements have been restated to correct this error. The effect of the restatement on those financial statements is summarised below.

Statement of Financial Position

Decrease in Investments (75,330)

Decrease in Accumulated Surpluses (51,390)

Statement of Financial Performance & Comprehensive Income

Decrease in Unrealised Gain/(Loss) on Investments (Non-Current) (23,940)

The impacted notes have been restated to reflect the correction - note 3 & 6.



8. Contingent Assets and Liabilities

The Association has no contingent assets and liabilities at 31 March 2020. (Last year - nil)

	Group 2020	Group 2019
9. Unused donations and grants with conditions		
Alexander McMillan Trust	15,500	15,500
Alex McLean Charitable Trust	-	3,000
AW Parsons	1,510	-
COGS Central Otago	2,000	-
COGS Costal Otago	3,000	-
COGS - Mataatua	-	139
COGS - Nelson/Bays	496	-
COGS -Tauranga-Moana	-	56
COGS - Tongariro	-	269
COGS - Whanganui/Waimarino/Rangitikei	-	2,000
Community Trust of Mid & South Canterbury	-	2,540
Dragon Community Trust	-	2,000
Dunedin Casino Charitable Trust	-	1,500
Epilepsy Foundation	20,000	-
Far North District	-	6,000
Foodstuffs	-	405
Foundation North	12,116	5,339
Great Lake Taupo	-	40
JN Williams Memorial Trust	1,788	-
L W Nelson Charitable Trust	4,000	-
Milestone Foundation	2,300	-
Nelson City Council	-	2,000
NZ Lottery	140,000	119,305
Pub Charity	-	89,963
Rata Foundation	859	10,000
Sir John Logan Campbell Residuary Estate	-	2,800
Skycity Queenstown Community Trust	1,097	-
Southland District Council	-	650
Taupo District Council	1,000	-
The Community Trust of Southland	1,735	-
The Lion Foundation	-	40,000
The Redwood Trust	-	1,000
The Trust Community Fund	5,000	-
TECT	1,169	-
Trust Waikato	1,426	-
Waikato WDFF Karamu Trust	770	-
W Duncan Bickley	2,641	1,795
Winton & Margaret Bear C/T	-	1,000
Total Unused donations and grants with conditions	218,407	307,301



Group
2020Group
2019**10. Commitments****Commitments to lease or rent assets**

Less than 12 months	21,591	19,524
More than 12 months but less than 5 years	18,035	8,122
More than 5 years	-	-
Total Commitments to lease or rent assets	39,626	27,646

11. Related Parties

		2020	2019	2018	2019	2018
Description of Related Party Relationship	Description of the transaction	Value of Transactions	Value of Transactions	Value of Transactions	Receivable/ (Payable)	Receivable/ (Payable)
Alison Nation was a board member until March 2019 and a partner at PKF Hamilton Ltd	PKF Hamilton Ltd provides accounting services to the Group	-	9,925	18,860	1,610	-

12. Ability to Continue Operating

The entity will continue to operate for the foreseeable future.

13. Events After the Balance Date

On March 25, 2020, the Government has announced that New Zealand moved to alert level 4 nationwide lockdown after World Health Organisation declared the outbreak of COVID-19 (a novel Coronavirus) a pandemic. As part of this lockdown measure all non-essential services are required to close. Epilepsy Association of New Zealand is considered as a non-essential service and the work premises were closed on 26 March 2020. We were able to remain in operation remotely and most staff were working their usual hours and our service delivery was largely unaffected.

At the date of issuing the Performance report, there is no significant impact on Epilepsy Association of New Zealand's performance report for the year ended 31 March 2020. At this time the full financial impact of the COVID-19 pandemic for the future year is not able to be determined, but it is not expected to be significant to Epilepsy Association of New Zealand. Epilepsy Association of New Zealand will continue to receive income from funding organisations / philanthropic organisations / Ministry of health.

14. Comparatives

There have been a few prior period comparatives which have been reclassified to make disclosure consistent with the current year.

