

GREETINGS FROM EPILEPSY NEW ZEALAND KIA ORA KOUTOU



FROM THE CHIEF EXECUTIVE'S DESK

A Season of Growth and Connection at Epilepsy New Zealand

Kia ora All,

As we head into spring (the blossoms are just starting to pop their heads out in my garden!), there's a real sense of momentum building at Epilepsy New Zealand. Behind the scenes, we've been working hard on several fronts, all while continuing to focus on delivering excellent service to our clients.

One of the most significant developments is the drafting of a new constitution. This is a vital step in ensuring our governance reflects the values and aspirations of our community and aligns with the requirements of the Incorporated Societies Act 2022.

We're also strengthening our collaborations with other organisations - especially those in the neurological space - to maximise opportunities to connect with more people, including in workplaces.

Advocacy is another area of renewed focus. I'm honoured to have recently been appointed to the newly formed Pharmac Consumer & Patient Working Group, which meets fortnightly to deliver an ambitious work programme (more on that below).

On a personal note, I'm absolutely thrilled to have recently brought our entire team - including the board - together in person for the first time. It was a powerful opportunity to connect, learn from one another and our wonderful presenters, and reinforce the shared purpose that drives our work every day.

Thank you for being part of this journey with us.

Ngā mihi nui
Tracy

[Email Tracy Here](#)



PHARMAC CONSUMER & PATIENT WORKING GROUP

The Consumer and Patient Working Group will provide insight, lived experience, and practical advice to ensure that the Pharmac reset programme is designed in a way that values and reflects the needs and perspectives of consumers and patients. The Consumer and Patient Working Group has been set up for the initial 12-month phase of the reset programme to lay the foundation for a more transparent, outward focused, and collaborative organisation and to support the wider reform of Pharmac.

The Consumer and Patient Working Group will provide advice for the reset programme but not advice on the funding of medicines by Pharmac, which falls outside the reset scope. The group will contribute to the wider reform of Pharmac, including the three workstreams of the reset programme which are:

- A new strategic vision
- Enhancing consumer engagement and trust
- Better processes

If you are interested in finding out more or following progress information will be regularly updated here

<https://www.pharmac.govt.nz/about/expert-advice/consumer-working-group>

[Pharmac Working Group Website](#)



SEPTEMBER IS WILLS MONTH

We're excited to partner with **Gathered Here** to make legacy giving as easy as possible for our supporters. As our gift to you, Epilepsy New Zealand supporters can write a will for free - just click the button below:

[Write your Will today!](#)

Wills written through Gathered Here are completely free and include **free updates for life**. No matter how many times your plans change, you can update your will easily.

If you choose to pledge a gift to the **Epilepsy Association of New Zealand Incorporated**, we will receive 100% of that gift when you pass away. Gathered Here never takes a cut - your generosity goes entirely to empowering people living with epilepsy.

Even if you're not ready to pledge a gift, you can still take advantage of this opportunity to write your **Will for free**.

Be part of our mission. Leave just 1% to Epilepsy New Zealand and make a lasting difference for people living with epilepsy.

[Click here to learn more](#)

PS: If we're already in your Will, thank you! We'd love to celebrate your generosity - drop [Bobbi](#) an email at marketing@epilepsy.org.nz



Ambassadors Wanted



COULD YOU HELP US FIND AN AMBASSADOR?

We're looking for well-known or influential people who could help Epilepsy New Zealand raise awareness and break down stigma by becoming an **ENZ Ambassador**.

If you know someone – a public figure, community leader, or someone with a strong presence – who could be a great fit, we'd love to hear from you.

Simply email marketing@epilepsy.org.nz with your suggestions and include your contact details and we'll be in touch shortly.

Together, we can amplify our message and celebrate life beyond epilepsy.

[Email Bobbi](#)



WAIKATO SUPPORT GROUP KEEPS GROWING

When our Waikato Educator was away recently, volunteer Tash stepped in to facilitate Epilepsy NZ's Waikato Support Group – and what a fantastic session it turned out to be! The group shared stories, challenges, and successes, creating an open and supportive space for everyone to connect. One partner even shared their perspective on seizures, offering insight that can be so valuable when a person can't remember what happens during an episode.

Tash also gathered ideas on what information and support people are looking for, which will help shape future sessions. Tash said, "As I have epilepsy, it's beautiful being part of something I believe in and that is helpful to me." It's clear the group is growing stronger every time, and to top it off, attendees even took home board games to enjoy with their families!



SPEAK UP FOR EPILEPSY FUNDRASIER

We're so lucky to have such a supportive and motivated community! Tracee from Ruakaka has taken the initiative to organise a fundraiser in support of epilepsy awareness and local support services. If you're in the Ruakaka area on November 29th, be sure to head along and show your support!

Feeling inspired? You can organize a fundraiser of your own—any time of the year! Or, start planning ahead and save the date for [Purple Day 2026](#).

If you'd like support or resources to get started with a fundraiser in your community, feel free to reach out to [Bobbi](#), our Fundraising and Marketing Manager

[Contact our Marketing and Fundraising Manager](#)



ENZ EDUCATORS IN THE COMMUNITY

Leanne visits Fern Collective

Otago-based educator Leanne recently visited *The Fern Collective*, an organisation supporting communities across Southland, Otago, Central Otago Lakes, North Otago, and the West Coast. Leanne provided training on epilepsy, which was well received—the team shared that it deepened their understanding and expressed their gratitude.

During her visit, Leanne was gifted a grief toolbox, a resource designed to support those experiencing bereavement. The Fern Collective has kindly offered to make these toolboxes available to any bereaved person we are working with.

Epilepsy Education at the Getting Out There EXPO 2025

Tiaho Trust once again hosted Te Tai Tokerau's largest event for accessibility, inclusion, and community connection — the *Getting Out There EXPO 2025*, held on Friday, 8 August in Whangārei. With this year's theme, "Accessible Horizons – Experience Inclusion," the event brought together people of all abilities, service providers, and community organisations, showcasing tools and services that support independent living.

Our Northland Educator, Reokore Johnson, attended alongside Epilepsy supporters Tracee and Kobi. Together, they enjoyed connecting with stallholders and attendees, raising epilepsy awareness, and strengthening links within the broader accessibility and inclusion community.



[ENZ Website](#)



YOUR EVERYDAY MOMENTS

♥ Help us grow our photo library – and celebrate life beyond epilepsy.

Do you, or someone you love, have epilepsy? We'd love to see photos of you living life to the fullest – at work, school, playing sport, enjoying hobbies, or spending time with friends and whānau.

Your photos will help us show that epilepsy doesn't define a person – they are so much more. Every image shared will help challenge stigma, raise awareness, and celebrate everyday moments that matter.

 Send your photos to marketing@epilepsy.org.nz.

By sending your photo, you're giving us permission to share it on our social media, website, and other promotional material. If you're under 18, please make sure a parent or guardian sends the photo.

Let's capture life beyond epilepsy, together. Thank you for helping us spread awareness and challenge stigma! ♥

[ENZ Website](#)

Navigating the Language of Epilepsy

Focal Seizures

Focal seizures, once known as partial seizures, start in a specific brain area within one hemisphere. Symptoms vary based on the affected region and awareness levels. They may remain localised or spread to other areas, possibly resulting in a generalised seizure.

www.epilepsy.org.nz



FIND US ON SOCIAL MEDIA

Have you visited our Facebook page recently?

In August, we ran a short miniseries called Navigating the Language of Epilepsy; through which we aimed to demystify some of the terms that may be used during your diagnosis.

Navigating The Language Of Epilepsy - Mini series 3
Just diagnosedand medical practitioners are talking about your epilepsy? They may be using terms you really don't understand but you don't want to ask what they're talking about.

We hope to break some of those barriers down by introducing some of the most commonly used terms.

For more information, go to our website
<https://epilepsy.org.nz/.../types.../focal-onset-seizures/>
Here is the link to FB <https://www.facebook.com/epilepsynz/>

[Register for our Newsletter](#)

Register for our newsletter



THANK YOU

♥ A massive thank you to **Cruickshank Pryde Lawyers** (cplaw.co.nz) for choosing Epilepsy New Zealand to receive a donation from the **Hugo Charitable Trust**!

This incredible support helps us provide vital education, resources, and assistance for people living with epilepsy and their whānau across Aotearoa.

We're so grateful for community champions like Cruickshank Pryde and the Hugo Charitable Trust for making a real difference. Together, we can create a more informed, understanding, and supportive environment for people living with epilepsy.

 Thank you for helping us change lives!

If your organisation would like to support the mahi of Epilepsy NZ, we would love to hear from you.

Contact our Fundraising and Marketing Manager

 **CRUICKSHANK PRYDE**
LAWYERS

Hugo
CHARITABLE TRUST

ONLINE TRAINING FOR TEACHERS

Become a **SeizureSmart** School
Register Now!

Please help us spread the word about
SeizureSmart schools in your area and share with
your whānau's school.

Let's make every school in New Zealand,
SeizureSmart!

LIMITED **FREE** TRAINING STILL AVAILABLE!

For Schools In:
Northland, Tauranga,
Eastern Bay of Plenty, Canterbury and
Hutt Region.



SEIZURESMART SCHOOLS

Do you have tamariki at school or are you a teacher?

Thanks to our generous funders free training for schools is
still available in: Northland, Tauranga, Eastern Bay of Plenty,
Canterbury and Hutt Region.

Epilepsy NZ's [SeizureSmart Schools](#) programme is an online
educational programme designed to be completed at your own
pace. It takes approximately 40 mins to complete. Please view our
other online training offerings in the links below.

[SeizureSmart Schools • Epilepsy New Zealand](#)
[SeizureSmart Workplaces • Epilepsy New Zealand](#)
[SeizureSmart Disability • Epilepsy New Zealand](#)

WE NEED YOUR SUPPORT

We urgently need your support to continue helping the 1 in 100
Kiwis living with epilepsy.

Our 13 dedicated educators are out in communities every day,
providing life-changing support, information, and guidance to
individuals and whānau - but we can't do it without you.

Every donation goes directly toward keeping these essential
services running. Please [give today](#) and help us be there for
those who need us most.

[Donate Now](#)



FREEPHONE
0800 37 45 37



If you require treatment advice please contact your health provider or ring 111 in an emergency

For general health advice, please ring 0800 611 116 - anytime

If you are experiencing mental distress, please call or text 1737 - anytime

Epilepsy New Zealand is a registered charity CC10611

Visit us at

www.epilepsy.org.nz

To unsubscribe [click here](#)