Epilepsy Matters

EPILEPSY NEW ZEALAND
Kia titiro ki te tangata | See the person
Celebrating 70 Years and Beyond

August 2026 Newsletter

Registered Charity: CC10611

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Epilepsy NZ's Chief Executive Tracy Tierney
at the Forbidden Pharmacy launch in Auckland

From The Chief Executive's Desk

Kia ora koutou,

Over the past couple of months, advocacy has been front and centre for ENZ. Together with our partners and supporters, we have been working hard to raise awareness of two critical issues facing people with epilepsy in Aotearoa: access to modern epilepsy medicines through the **Forbidden Pharmacy** campaign, and the urgent shortage of neurologists through the **Train Five, Keep Five** campaign.

With a General Election approaching, now is an important time to ensure these issues are heard. I encourage everyone to support these campaigns by signing the letters of support and raising these concerns with your local MP and election candidates. Real change happens when decision-makers hear directly from the people affected. Every conversation helps build understanding, and every voice strengthens the call for better outcomes for people living with epilepsy.

On a personal note, I was honoured to recently be appointed to Pharmac's Interim Consumer Transition Committee (ICTC). This appointment follows my involvement in Pharmac's Consumer and Patient Working Group, which has now concluded.

The ICTC provides Pharmac with input from a consumer perspective and will help shape Pharmac's future advisory function going forward. While I will be bringing the experiences of people living with epilepsy and other health conditions to those discussions, the appointment also provides an important opportunity to ensure the voices of patients, whānau and communities continue to be heard in decision-making about medicines and health services.

There has also been plenty happening across ENZ as we prepare for our upcoming AGM, continue to strengthen our services, and build new connections throughout the epilepsy community. Whether you're a member, volunteer, supporter, client, whānau member or partner organisation, thank you for being part of the ENZ whānau and standing alongside us.

As the days begin to lengthen and spring approaches, I hope we can all take encouragement from the opportunities ahead. Progress can sometimes feel slow, but positive change happens when people come together around a shared purpose.

Thank you for your ongoing support, your advocacy, and your commitment to creating a better future for people living with epilepsy.

Ngā mihi nui,

TRACY TIERNEY
CHIEF EXECUTIVE

Email Tracy Here

Discontinuation: Sodium valproate (Epilim) 100mg crushable tablets

Sanofi, the supplier of Epilim, has notified Pharmac that Epilim 100mg crushable tablets are being discontinued globally. Sanofi expects available stock to last until the end of November 2026.

Other Epilim products are not affected and will remain available, including: Epilim Sugar-Free Liquid, Epilim Syrup, Epilim 200mg EC tablets, Epilim 500mg EC tablets

What this means for people taking Epilim 100mg crushable tablets

If you or someone you support is currently taking Epilim 100mg crushable tablets, you will need to speak with your prescriber to discuss and arrange a suitable alternative treatment.

Do not stop taking your medication or make any changes to your treatment without first consulting your doctor or prescriber.

For more information, please see the **Epilim discontinuation information on the Pharmac website.**

Hon Simeon Brown, Minister of Health and Tim Edmonds, Forbidden Pharmacy campaign spokesperson at the Forbidden Pharmacy Launch

Add Your Support to the Forbidden Pharmacy Campaign

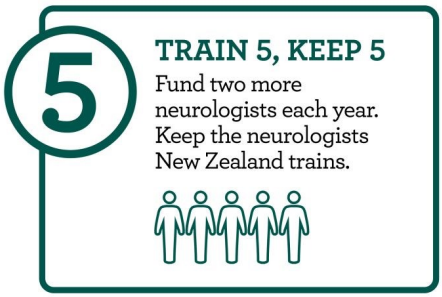
Although the **Forbidden Pharmacy** activation has come to an end, we're asking our community to keep the momentum going by **adding their support**.

This powerful campaign is bringing together people and organisations from across Aotearoa to call for better access to the medicines people need.

You can help by adding your name to the open letter and showing your support.

Every name strengthens the call for change.

Add your support today and help make your voice count.



Neurological Alliance of New Zealand

Support the Train 5, Keep 5 Campaign

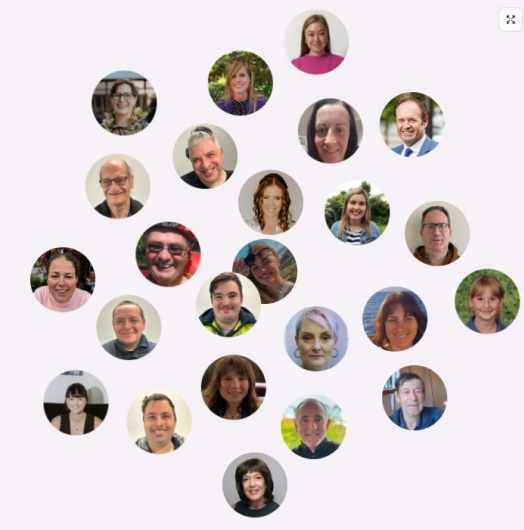
We're asking our community to get behind the **Train 5, Keep 5** campaign, which is calling for urgent action to address the shortage of neurologists in Aotearoa New Zealand.

Neurologists play a vital role in the diagnosis, treatment and ongoing care of people living with neurological conditions, including epilepsy. However, New Zealand is facing a significant shortage of these specialists, making it increasingly difficult for people to access the timely and expert care they need.

The **Train 5, Keep 5** campaign is calling on the Government to commit to training at least five new neurologists each year - while also ensuring New Zealand can retain at least five neurologists in the workforce. By investing in the neurological workforce now, we can help improve access to specialist care for the thousands of New Zealanders living with neurological conditions.

Add your support today and help us call for a stronger neurological workforce and better access to care for everyone who needs it.

Add Support



Faces of Epilepsy – Celebrating 70 Years

As part of our 70th birthday celebrations, we're proud to launch Faces of Epilepsy – a campaign celebrating the people at the heart of Epilepsy New Zealand.

For 70 years, we've been supporting people affected by epilepsy across Aotearoa. Faces of Epilepsy brings this to life by sharing the experiences, voices and realities of people living with epilepsy, helping to build understanding and show the person behind the diagnosis.

A huge thank you to everyone who has contributed so far by sharing their experience and being part of this special campaign. Your stories help us celebrate our past while highlighting why our work continues to be so important.

Meet the Faces of Epilepsy:
Faces of Epilepsy • Epilepsy New Zealand
(https://epilepsy.org.nz/understanding-epilepsy/faces-of-epilepsy/)

And it's not too late to take part! If you'd like to share your experience, email Bobbi at marketing@epilepsy.org.nz to find out more.

Faces of Epilepsy website page

Supporting the Next 70 Years and Beyond

As we celebrate **70 Years and Beyond**, we are reflecting on the incredible journey so far and looking ahead to the future of supporting people living with epilepsy across Aotearoa.

To help us continue this vital work, we're inviting our community to mark the occasion with a special one-off gift of

- **$7.00**
- **$70.00**
- **$700.00**

Or, perhaps you could choose to make a regular monthly donation, helping provide ongoing support well into the future.

Every donation, no matter the size, helps ensure we can continue providing information, education and support for people living with epilepsy and their whānau for the next 70 years and beyond.

To donate, simply click on the box below, choose **Donation Allocation – Celebrating 70 Years and Beyond**, and enter a donation amount that feels right for you.

Donate Here

Celebrating 40 Years of Community Connection at the Top of the South Island.

Epilepsy New Zealand was delighted to be part of the celebration marking 40 years of Community and Whānau Meetings in Nelson Tasman, held at the Motueka RSA. Theresa Kidd-Foley represented Epilepsy New Zealand at the event and presented a commemorative poster celebrating ENZ educators who have supported the Nelson Tasman region over the years.

Community meetings were started by Penny Molar whose extraordinary contribution to the community has been recognized by a Queen's Service Medal and a Nelsonian Civic Award. The meetings have provided a welcoming space for connection, support, information sharing, and friendship for countless people living with epilepsy and their whānau.

Read ENZ Blogs Here

Looking For Businesses To Support Us

Corporate sponsorship is a powerful way for businesses to show their commitment to social impact, while helping us continue providing vital support, education, and advocacy for people living with epilepsy.

We're always looking for meaningful partnerships with organisations that want to make a real difference in their communities.

If you know someone - whether it's a colleague, friend, connection, or even you - we'd love an introduction. A simple conversation could 'open the door' to a partnership that benefits both their business and the thousands of people we support each year.

Feel free to get in touch or pass on our details. We'd be happy to chat and explore what a partnership could look like.

Email Bobbi Here

SEIZURESMART ONLINE LEARNING

Become SeizureSmart Today!

Our SeizureSmart online training is an easy-to-follow course designed to build confidence and understanding around epilepsy and seizure first aid. In just a short time, you'll learn how to recognise different types of seizures and how to respond safely and calmly if one occurs.

Whether you're a teacher, coach, employer, community group member, or simply want to be better prepared, this training helps create safer, more supportive environments for people living with epilepsy.

Learn at your own pace, anytime, anywhere - and become SeizureSmart today!

To get started, visit Epilepsy New Zealand's website or contact us for more information.

SeizureSmart Schools • Epilepsy New Zealand
SeizureSmart Workplaces • Epilepsy New Zealand
SeizureSmart Disability • Epilepsy New Zealand
SeizureSmart Whānau • Epilepsy New Zealand

everywill

September is Wills Month

September is **Wills Month** – a great reminder to make or update your Will and make sure your wishes are known.

Having a Will gives you peace of mind that the people and causes that matter to you are looked after in the future. It's also an opportunity to leave a lasting legacy by remembering **Epilepsy New Zealand** in your Will.

Through our partnership with **EveryWill**, you can make a legally valid Will online for free, with the option to include a gift to Epilepsy New Zealand if you choose.

A gift in your Will, no matter the size, can help us continue providing information, education and support to people living with epilepsy and their whānau across Aotearoa for years to come.

Make your free Will with Everywill this September and give yourself – and your loved ones – peace of mind

If you already have a Will, Wills Month is also a good time to check that it still reflects your wishes.

To find out more about leaving a Bequest - CLICK HERE

Shout Out To Our Funders

We would like to sincerely acknowledge and thank the following funders for their generous support of our mahi across Aotearoa:

- Pub Charity
- COGS (Community Organisation Grants Scheme)
- The Lion Foundation
- Rātā Foundation
- Disability Community Trust
- A.C.E Shacklock Trust (*managed by Wilkinson Rodgers Lawyers)*
- Rehabilitation Welfare Trust

This support enables us to continue making a meaningful difference in communities around the motu. Thank you!

Please 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.
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Visit us at
www.epilepsy.org.nz