

## **Co-chairpersons' Report for the 2024 AGM of the Epilepsy Waikato Charitable Trust**

### *Welcome and Acknowledgements*

Tēnā koutou, tēnā koutou, tēnā koutou katoa.

Ngā mihi nui ki a koutou i tēnei rā. Nau mai, haere mai ki te hui a-tau o te Epilepsy Waikato Charitable Trust. Nō reira, tēnā koutou, tēnā koutou, tēnā tātou katoa.

Welcome to the 2024 Annual General Meeting of the Epilepsy Waikato Charitable Trust (EWCT). I am honoured to present this report as one of the co-chairs of our dedicated organisation. I extend a warm welcome to our members, clients, trustees, and guests here today.

Firstly, I would like to acknowledge the incredible efforts of my fellow trustees and volunteers, whose dedication and hard work continue to drive our mission forward. Special acknowledgements go to our office holders: Tracey Morgan, who serves as our funding manager in addition to co-chair; Ashita Bhudia, our diligent treasurer; Cyril Markham, who manages our alarm sales and David Nicolls, who serves as secretary to the Board. Your commitment and service are invaluable to the trust. Special thanks go to Maria Lowe, our epilepsy advisor until January 2024, and Esther Liddle, who took over the role in November 2023. Their commitment to providing advice, advocacy, and support to individuals with epilepsy and their families is at the heart of our mission.



Figure 1: The EWCT Trust Board as at November 2023

### *Governance and Leadership Changes*

This year marked a significant leadership transition for EWCT. David Lowe, who has been a stalwart leader and chair of the Trust, retired from his position. Under his guidance, EWCT has grown in scope and impact, and we are deeply grateful for his dedication and service. I want to thank Karl Bentley for stepping into a caretaker role until we transitioned to a co-chair leadership model that recognises the evolving needs of our organisation.

Long-serving trustees Faith Gibbs and Bryce Hopkins stepped down in 2023 while Tracey Morgan and I also joined the Board of Trustees in May 2023 and February 2024 respectively. An 'Epilepsy Hero Award' was made to Susanne Llopis from the Waikato District Health Board in 2023.

It has been an honour to step into this role and work alongside such a dedicated team.

## *Overview of Activities in 2023-2024*

EWCT's mission is to support people with epilepsy, along with their families, friends, and communities, primarily in the Waikato region but also beyond. Over the past year, we have continued to provide essential services, including one-on-one advice, action plans, and advocacy. Our outreach through epilepsy talks, in-service training, and networking has also expanded, helping to demystify epilepsy and promote understanding.

### **Some key achievements include:**

- (a) *Supporting Individuals and Families:* We provided personalised epilepsy action plans and advocacy services for clients, working closely with medical professionals and community agencies to ensure comprehensive support.
- (b) *Education and Advocacy:* EWCT conducted numerous talks and training sessions for schools, workplaces, and community groups. We also maintained active participation in national-level advocacy, including our petition to Parliament to fund vagal nerve stimulation (VNS) therapy for adults with intractable epilepsy.
- (c) *Publications and Resources:* In February 2023, we published "A Quick and Easy Read About Epilepsy," our fifth book aimed at making information accessible to diverse audiences. The book was well received, necessitating a second print run in May 2023. Additionally, we continued to distribute our established publications, which include guides and resources for both children and adults. Our books have been extremely popular to the point we are now having to seek funding for reprints of "Bens Buddies", "a Quick and Easy Read (2023)", and "Understanding and Managing Epilepsy (2<sup>nd</sup> Edition)". We are also looking to get some of our books translated to provide greater accessibility for our communities.
- (d) *Epilepsy Awareness Month:* November was marked by a range of activities aimed at raising awareness and engaging the community. These included social media campaigns and the distribution of educational materials.
- (e) *Community Engagement and Fundraising:* Our volunteers and trustees worked tirelessly to run events, including the Wellbeing Show and Women's Lifestyle Expo, and to maintain our fundraising efforts through grant applications, sausage sizzles, and other community initiatives.

### *National Initiatives*

EWCT remains committed to advocating for national-level improvements in epilepsy care. Our ongoing efforts include:

- (a) *Petition for VNS Therapy:* Our petition urging Te Whatu Ora Health New Zealand to fund VNS therapy was presented to Parliament in July 2023. We are hopeful for positive outcomes from the Parliamentary Health Committee's review.
- (b) *Advocacy for Ketogenic Services:* Despite promises from Waikato Hospital, the development of a ketogenic diet service remains incomplete. EWCT has actively pursued this matter, including lodging a formal complaint with the Ombudsman.

### *EWCT agency status for Seizure Alert Australia*

EWCT holds status as the sole New Zealand agent for Seizure Alert Australia, which supplies alarms and other devices for monitoring people with epilepsy (<https://www.seizurealertaustralia.co.nz/>). In January 2023 a formal contract was completed by EWCT with Seizure Alert Australia. The agency allows EWCT to provide another service to its clients in the Waikato region, and elsewhere in New Zealand, and also raise funding through commissions.

## *Financial Performance*

EWCT's financial position remains stable, with a surplus of \$13,325 for the year ended 31 March 2024. Our main funding sources continue to be grants, donations, and fundraising activities, all of which are crucial for sustaining our services. We are grateful to all our supporters, including Margaret Davidson, NZ Lotteries Grant Board, DV Bryant Trust, Glenice and John Gallagher Foundation, Community Organisation Grants Scheme (COGS), Trust Waikato, WEL Energy Trust Community Grants, Lions Clubs International (Waikato region), The Lions Foundation (Auckland), Hamilton City Council Community Funding, PCL Group (Waikato Print), Bunnings (South Hamilton), and Brinkworth Associates. Their generous contributions enable us to continue our work.

## *Conclusion*

Looking ahead, we remain focused on expanding our services and advocating for better support for individuals with epilepsy across the Waikato. The dedication of our staff, volunteers, trustees, and supporters is the cornerstone of our success, and I am confident that together, we will continue to make a meaningful impact in the lives of those we serve.

Thank you all for your continued support and commitment to EWCT.

*Ngā mihi nui,*

**Tracey Morgan and Stephen Harlow**

Co-Chairs, Epilepsy Waikato Charitable Trust