

## Epilepsy Waikato Charitable Trust AGM, 8<sup>th</sup> September 2020

### Chair's report

I welcome all attendees at the 2020 AGM of EWCT – members, clients, family supporters, trustees, and guests. Now at the end of our ninth year, I firstly thank the board of trustees, especially the office holders, Jill Davies (funding manager and deputy chair), Emma McNeil (treasurer), and administrator Margaret Paine, for their commitment to achieve the aims of the trust, and for their support for me as chair. We have had one change to the board this year: Emma McNeil, treasurer, resigned from 10 March 2020, but continued through to August 2020 as acting treasurer (aided by Cyril Markham). Emma's great work has been much appreciated. We remain very grateful to our patron, Hon. Tim Macindoe (MP for Hamilton West), for his enduring support of EWCT. I am pleased to record that EWCT won the **"Team Excellence Award"** in the Volunteering Waikato annual awards event on 20 June 2019. This is the premiere award of Volunteering Waikato and endorses the work of the EWCT Trust.



**Sponsors and donors** I acknowledge and thank all who have donated to EWCT or sponsored our trust's work over the last year. We are supported by donors (private individuals) and numerous funding organisations, who provide us with significant funds or 'in kind' support. The funders include NZ Lotteries Grant Board, Gallagher Charitable Trust, DV Bryant Trust, Glenice and John Gallagher Foundation, Community Organisation Grants Scheme (COGS), Trust Waikato, Len Reynolds Trust, Hamilton City Council Community Funding, Sir John Logan Campbell Residuary Estate, and

Waikato Print (Gravitas). All funders are acknowledged on our website and on our letterhead documents. Trustees and supporters also organised and ran several fund-raising events including garage sales, raffles (at expo events), a special fund-raising luncheon, several sausage sizzles, and by selling copies of the 'Entertainment Book'. As well as raising funds, these events also provide awareness of epilepsy and EWCT in the community.

**Epilepsy advisor** Board members wish to thank **Maria Lowe**, our full-time epilepsy advisor, for her continuing hard work in helping many people with epilepsy in our community. Maria reports to the board each month. Her role encompasses many aspects of support, advice, and education including:

- (i) providing one-on-one advice to people with epilepsy and their families, friends, and workmates, including interaction with neurologists and hospital referrals;
- (ii) preparing client-specific epilepsy action plans for clients, caregivers, and employers;
- (iii) advocacy for members in meetings or via correspondence with medical practitioners, government agencies (e.g. Dept. of Social Welfare, Work and Income, Housing NZ, Corrections), hospitals, law firms, and courts;
- (iv) interviews on the radio (available as podcasts on the website);
- (v) educating through talks, including at schools, and providing in-service training about epilepsy;
- (vi) writing fact sheets for the EWCT website (we now have 30 fact sheets in total including the popular 'A to Z directory of epilepsy' and 20 activity sheets for children);

- (vii) running displays at expos including the 'Wellbeing Expo', 'Women's Expos' in May (Hamilton) and August (Tauranga), and a new 'Aspire' expo;
- (viii) coordinating and helping to run Epilepsy Club events for members and clients such as the bi-monthly Fresca Café get-togethers in Hamilton and also at Tokoroa, Te Awamutu, Morrinsville (new group), and Tauranga;



- (ix) organising activities for 'Epilepsy Awareness Month' in November, which in 2019 included the very successful 'We are...' project (<https://ewct.org.nz/we-are-project/>). It is centred on reducing stigma, prejudice, and fear within families and communities around the condition of epilepsy, and comprised a large poster and accompanying booklet. As well, EWCT participated in the annual Round-the-Bridges event;
- (x) communicating with members, clients and supporters through Facebook, 'Leading the Way' newsletters, monthly epilepsy research news, and our website ([www.ewct.org.nz](http://www.ewct.org.nz));
- (xi) our website 'views' and 'visitors' continue to show the importance and impact of the site with an average of 9200 visitors and 21,340 views annually for the past two financial years;
- (xii) designing and preparing posters for displays and the website;
- (xiii) attending and participating in networking meetings with various community organisations in the Waikato region; and
- (xiv) one of our books, "Ben's Buddies", is now an animated video in three languages: English, te reo Māori, and German (<https://ewct.org.nz/product/bens-buddies-epilepsy-childrens-story-book>).

**New book** During the lockdown because of Covid-19, Maria Lowe worked on a new book "Understanding and managing epilepsy". The book, for which there is considerable interest, is to be published by EWCT in 2021, partly to celebrate EWCT's 10<sup>th</sup> anniversary year.

**Awards** On 29 June, 2019, stalwart member of EWCT, **John Fayerman**, and former trustee and volunteer secretary, **Ai Ee Teo**, were presented with **Epilepsy Hero awards** for 2019. Long-serving trustees, **Cyril Markham** and **Faith Gibbs**, were awarded **inaugural life memberships** of EWCT in June and July 2019, respectively.

**National level contributions** (i) Maria Lowe took part in a teleconference with the Parliamentary Health Committee (PHC) in May 2019 following EWCT's petition to Parliament presented by Hon. Tim Macindoe in October 2018. The petition requested that a **ketogenic dietitian and support programme be funded by the Waikato DHB** to help people living with intractable epilepsy. The PHC's Final Report (September 2019) fully supported the petition's intent, as did Director-General of Health, Dr Ashley Bloomfield. Earlier, in April 2019, EWCT hosted a public lecture (by Dr Matt Phillips) on the ketogenic diet and its efficacy in treating intractable epilepsy. The Waikato DHB in October 2019 acknowledged receipt of PHC's Final Report and EWCT's request for action, and said that the ketogenic dietitian and a hub-and-spoke model for servicing the region (as occurs in South Island DHBs) would be considered. (ii) EWCT sent three **letters of concern to PHARMAC** on the change to the funding of lamotrigine to a generic substitute used in the treatment of epilepsy and/or bipolar disorder. EWCT's position is that the switch is potentially deleterious to many people in various ways. Seven deaths that may relate to the switch are being investigated by the coroner. All correspondence is on EWCT's website. (iii) In May 2019, a submission was made by EWCT to the **review of the Charities Act 2005** being carried out by the Department of Internal Affairs.

In closing, I record that EWCT continues to work well (including in the Covid lockdown in March-April 2020). All can be pleased and proud of EWCT's achievements over the past year.

**David J. Lowe** – Chair, EWCT