

Epilepsy Waikato Charitable Trust AGM, 10th September 2019

Chair's report

I am pleased to welcome all attendees at the 2019 AGM of EWCT – members, clients, family supporters, trustees, and guests. Now in our eighth year, I firstly thank the board of trustees, especially the office holders, Jill Davies (funding manager and deputy chair), Emma McNeil (treasurer), and Margaret Paine, our administrator since 2 April, 2018, for their commitment to achieve the aims of the trust, and for their support to me as chair. We have had one change to the board this year: Stephanie Hetaraka, a foundation trustee, resigned effectively in April 2019 and her support over more than seven years has been greatly appreciated. The deeds of long-serving **Faith Gibbs** and **Cyril Markham**, for EWCT and Epilepsy Waikato over many decades before 2011, were recognised in late June with the inaugural award of **life membership** to both by EWCT. We remain very grateful to our patron, Hon. Tim Macindoe (MP for Hamilton West), for his enduring and substantial support of EWCT. I am especially pleased to record that EWCT won the “**Team Excellence Award**” in the Volunteering Waikato annual awards event on 20 June 2019, which attests to the impact our organisation is making in the region and beyond.



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 Trust, DV Bryant Trust, Glenice and John Gallagher Foundation, WEL Energy Trust, Community Organisation Grants

Scheme (COGS), Trust Waikato, Len Reynolds Foundation, Hamilton City Council Community Funding, Norah Howell Trust, and Sir John Logan Campbell Residuary Estate. 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, and sausage sizzles, and by selling copies of the 'Entertainment Book'.

Epilepsy advisor Board members wish to thank **Maria Lowe**, our full-time epilepsy advisor, for her hard work in helping many people with epilepsy in our community. Maria was presented with a **Hamilton Civic Award** by Mayor Andrew King on 14 December, 2018 (see photo below) for her “outstanding contribution to Hamilton with services to health and the 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 (usually available as podcasts on the website);

(v) educating through talks, including at schools, and providing in-service training about epilepsy, and writing fact sheets for the EWCT website (we now have 29 fact sheets in total including the popular ‘A to Z directory of epilepsy’);

(vi) running displays at expos including the Waikato ‘Wellbeing Expo’ in April, the Waikato ‘Women’s Expo’ in May, and two further expos in Thames and Tauranga;

(vii) 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, Huntly, Tauranga, Te Awamutu, and Morrinsville (new group);

(viii) organising activities for ‘Epilepsy Awareness Month’ in November, which in 2018 included the very successful ‘Postcard Project’ (<https://ewct.org.nz/postcard-project/>) as well as EWCT’s participation in the Round-the-Bridges event;

(ix) communicating with members, clients and supporters through Facebook, ‘Leading the Way’ newsletters, monthly epilepsy research articles, and our website (www.ewct.org.nz);

(x) our website ‘views’ and ‘visitors’ continue to increase each year, showing the importance and impact of the site – e.g., for three years 2017–2018–2019, ‘visitors’ have totalled 3862–6009–9449, respectively; ‘views’ have totalled 18,380–21,325–21,681, respectively;

(xi) designing and preparing posters for displays and the website; and

(xii) helping to develop and publish our books, with “Ben’s Buddies” now available as an animated video in three languages, English, te reo Māori, and German: <https://ewct.org.nz/product/bens-buddies-epilepsy-childrens-story-book>

Reprints of our two books Although we launched our second book “Ariana and Jack” only in March 2017, it was reprinted in May 2018 to ensure we could keep up with demand for its use. At the same time, we reprinted “Ben’s Buddies” (first published in 2014), which was nearly out of stock. The reprints were funded by grants from the Hamilton City Council and the Sir John Logan Campbell Residuary Estate, together with proceeds from book sales.

Epilepsy Hero Award On 7 July 2018, the annual award was made to **Antony Booker**, our outstanding webmaster. On 29 June, stalwart member of EWCT, **John Fayerman**, and former trustee and volunteer secretary, **Ai Ee Teo**, were presented with the awards for 2019.

National level contributions (i) Maria Lowe initiated a **Parliamentary Petition** in August–September 2018 on behalf of EWCT. It was presented to Parliament on 16 October by Hon. Tim Macindoe with 507 votes. The petition, supported by Dr Matthew Phillips of the Neurology Department, Waikato Hospital, requested that a **ketogenic dietitian** and support programme be funded by the Waikato DHB to help those people living with intractable epilepsy in our region. A written submission was made to the Health Committee in November 2018, followed by an oral presentation via teleconference by Maria in late May 2019. A well-attended public seminar by Dr Phillips on the topic of ketogenic diet for adults with epilepsy was held on 9 April 2019. (ii) In September, 2018, a **letter of concern was sent to PHARMAC** by EWCT on proposed changes to the funding of lamotrigine and other drugs used in the treatment of epilepsy and/or bipolar disorder, which were to be replaced by generic substitutes. (iii) Most recently (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 am pleased to advise that EWCT is working well. All involved can be pleased with EWCT’s achievements, and that some of the hard work has been recognised with two awards.

David J. Lowe – Chair, EWCT