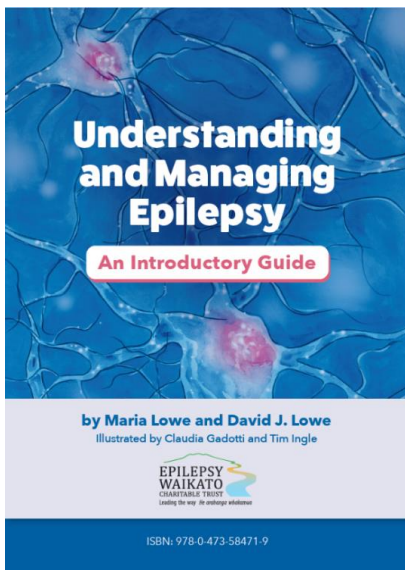


Epilepsy Waikato Charitable Trust AGM, 14th September 2021

Chair's report

Welcome

I welcome all in attendance at the 2021 AGM of EWCT – members, clients, family and other supporters, trustees, and guests. Now at the end of our 10th anniversary year, I firstly thank the board of trustees, especially office holders Jill Davies (funding manager, deputy chair) and Cyril Markham (treasurer), and also administrator Margaret Paine, for their hard work and commitment to achieve the aims of the trust. I warmly welcome newly appointed trustee, Karl Bentley, to the board. I additionally thank our webmaster, Antony Booker, for his ongoing excellent work on our behalf. I remain especially grateful to our patron, Hon. Tim Macindoe (former MP Hamilton West), for his enduring support of EWCT.



New book

Undoubtedly a highlight this milestone year has been EWCT's publication in August of a substantial book on epilepsy, the writing of which was led by Maria Lowe, our full-time epilepsy advisor. The book is the first general book on epilepsy to be published in New Zealand in more than 30 years. It describes at an introductory level the complex nature of epilepsy, its potentially life-long impacts, and its management. We are very grateful to the Harcourts Foundation for a grant for printing and other costs. The book was illustrated by Claudia Gadotti and Tim Ingle, and Tim also designed the book and developed the final layout ready for printing by PCL Group (printery on Waikato University's Hamilton campus). The book is the third to be published by EWCT.

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/supporters include NZ Lotteries Grant Board, DV Bryant Trust, Glenice and John Gallagher Foundation, Community Organisation Grants Scheme (COGS), Trust Waikato, WEL Energy Trust, EFNZ Perpetual Guardian, Hamilton City Council Community Funding, Legacy Trust (Tauranga), Harcourts Foundation, PCL Group, Brinkworth Associates (chiefly Darrell Bowler and Ashita Bhudia, who generously assisted us with financial matters), and Stephen Turner, who has kindly helped with legal matters.

Trust board and administrator roles

As well as meeting monthly, the board – well supported by our administrator – keeps track of accounts, minutes proceedings, approves expenditure, completes annual financial and service auditing requirements, and completes requirements for the Charities Services. The board applies for funding from multiple organisations (on average one or two applications per month), meets with funders, and prepares reports for them, prepares documents for the AGM, attends and contributes to network meetings, helps run social events (including the Epilepsy Hero award), contributes to expos, and prepares occasional media releases. The board, administrator, and supporters also organise and run local fund-raising events including sausage sizzles at Bunnings, raffles at expo events, and earns commissions from sales of the 'Entertainment Book'. As well as raising funds, these and other events help provide awareness of epilepsy and EWCT in the community.

Epilepsy advisor roles

Board members thank Maria Lowe (epilepsy advisor) for her continuing and extraordinary diligence in helping many people with epilepsy, and others associated with them, in our community. Maria reports to the board each month. As well as (co)writing the new book over the past 18 months, her roles in 2020-21 encompassed many aspects of support, advice, advocacy, and education including:

- (i) providing one-on-one advice to people with epilepsy, including new clients, and their families, friends, and workmates, as well as interaction with neurologists, paediatricians, 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/WINZ, Housing NZ, Corrections), social service providers, hospitals, law firms, courts, schools, and private employers;
- (iv) educating through talks and providing in-service training about epilepsy to a wide range of agencies including social service providers, private companies, and schools;
- (v) attending and participating in networking meetings with various community organisations;
- (vi) preparing monthly reports and data for EWCT trustees;
- (vii) assessing clients to qualify for 'total mobility' status with documentation for the Waikato Regional Council;
- (viii) running displays at expos (Wellbeing, Women's, Aspire) in Tauranga and Hamilton;
- (ix) coordinating and helping to run Epilepsy Club events for members and clients including the bi-monthly Fresca Café socials in Hamilton, Tokoroa, Te Awamutu, Morrinsville, and Tauranga;



(x) organising activities for 'Epilepsy Awareness Month' in November, which in 2020 included the wonderful 'Phone chat' project (<https://ewct.org.nz/category/phone-chat/>). The protagonists used their own words to describe their experiences, challenges, and accomplishments in living with the condition, their overriding aim being to have their voices heard; and EWCT participated in the annual Round-the-Bridges event;

(xi) communicating with members, clients and supporters through Facebook, 'Leading the Way' newsletters, monthly epilepsy research news, and our website (www.ewct.org.nz);
 (xii) our website continues to show its importance with an

average (for the last three financial years) of 9285 visitors, 11,365 sessions or visits, and 21,170 views annually;

- (xiii) writing and updating fact sheets for the website (we have 31 fact sheets with 20 activity sheets for children); and
- (xiv) designing and preparing material for displays and the websites, such as posters for first aid.

Award

To recognise exceptional support to others who have helped the Trust achieve its goals, the annual Epilepsy Hero award for 2020 was made to **Neil Fynn** (Cambridge).

National-level contributions

(i) *Ketogenic dietician*: Our petition to Parliament (Oct 2018) requested that a ketogenic dietitian and support programme be funded by the Waikato DHB to help people living with intractable epilepsy in the region. The Parliamentary Health Committee's report (Sep 2019) supported the petition's intent as did Director-General of the Ministry of Health, Dr Ashley Bloomfield, who also stated his expectation of equitable service delivery across the country. However, our request has still not been fulfilled and now, after three requests to the Waikato DHB under the Official Information Act (Feb 2019, Jan 2020, April 2021), EWCT has laid a complaint (June 2021) with the Ombudsman about the Waikato DHB's lack of commitment to making an appointment.

(ii) *PHARMAC medication changes*: EWCT sent three letters of concern to PHARMAC and two letters to the Health Select Committee (Jul and Aug 2020) on the change to the funding of lamotrigine to a generic substitute (Logem) used in the treatment of epilepsy. EWCT's position is that the switch was potentially deleterious to many people in various ways. We summarised our objections in a letter to Hon. Andrew Little (Minister of Health) in May 2021. Most recently, we sent comments to PHARMAC (June 2021) about the cessation of supply of gabapentin and primidone to New Zealand from Oct 2021. All correspondence is on EWCT's website.

An exceptional year

In closing, I am pleased to record that EWCT continues to maintain very high standards in serving the epilepsy community and associates. As well as coping with the Covid lockdown (March-May 2020) and various related difficulties, EWCT can reflect on an anniversary year in which its achievements have been exceptional, and we can be very proud indeed of our organisation and its supporters and members, and our accomplishments.

David J. Lowe – Chair, EWCT