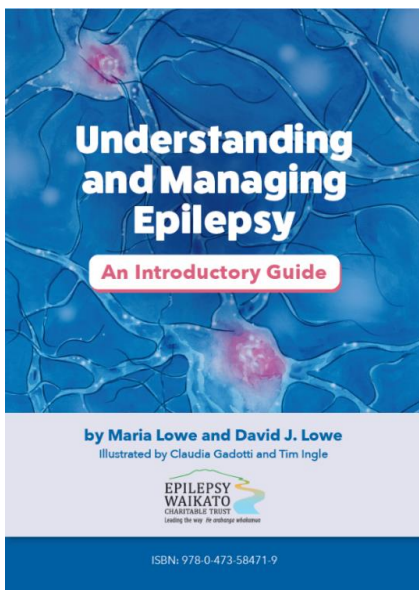


Welcome

I welcome all in attendance at the 2022 AGM of EWCT – members, clients, trustees, and guests. I wish to firstly acknowledge and thank all trustees, especially office holders Jill Davies (funding manager, deputy chair) and Cyril Markham (treasurer), and administrator Margaret Paine, for their work and commitment to achieve the aims of the trust. I record my gratitude to our webmaster, Antony Booker, for his work on our behalf. I am very grateful to our patron, Hon. Tim Macindoe (former MP Hamilton West), for his ongoing support of EWCT.



New book: “Understanding and Managing Epilepsy”

Undoubtedly a highlight of the past financial year has been EWCT's publication, in September 2021, of its new book on epilepsy, the writing of which was led by Maria Lowe, EWCT's full-time epilepsy advisor. The publication, reported at the AGM last year and the first general book on epilepsy to be published in New Zealand in more than 30 years, has been very well received. The fourth book to be published by EWCT, it is in three parts: Part 1 is about understanding epilepsy; Part 2 is about its management; and Part 3, entitled “Living with epilepsy”, comprises a set of compelling stories by 12 people who have epilepsy or who support or care for someone with epilepsy. At the end is a glossary and two first-aid illustrations that can be printed as wall posters. One hundred copies of the book were given to the Neurology Department of Waikato Hospital on 30 September 2021 (see <https://dailyencourager.co.nz/new-hope-for-understanding-and-managing-epilepsy/>), and more than 60 free copies have been donated to every public library branch in the Waikato region. The trust is going to publish a reprint of the book soon. EWCT's

seizure diary continues to provide an essential document for both clients and medical staff, and we printed more copies in 2021 to enable us to cope with ongoing demand.

Sponsors and donors

I and trustees 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, Gallagher Foundation, Community Organisation Grants Scheme (COGS), Trust Waikato, Epilepsy Foundation (EFNZ) Perpetual Guardian, Hamilton City Council Community Funding, A & M Parbhu Foundation, Harcourts Foundation, PCL Group, DTI Lawyers, and Brinkworth Associates. We are especially grateful to Darrell Bowler and Ashita Bhudia of Brinkworths, who generously assist our treasurer with financial expertise each month and annually for audit requirements.

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, undertakes banking and payments, and completes annual financial and service auditing, and other requirements including for 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, contributes to expos (none in 2021 because of COVID), 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.

Agency for Seizure Alert Australia-New Zealand

EWCT, the sole New Zealand agent for Seizure Alert Australia (<https://www.seizurealertaustralia.co.nz/>), has begun supplying a number of alarms and other devices that help monitor people with epilepsy in New Zealand.

History of EWCT – 10th anniversary

To mark the 10th anniversary of EWCT in 2021, a summary of our history, including that of Epilepsy Waikato, was published on our website (<https://ewct.org.nz/history-of-epilepsy-waikato/>)

Epilepsy advisor roles

Board members thank Maria Lowe (epilepsy advisor) for her continuing diligence in helping many people with epilepsy, and others associated with them, in our community. As well as (co)writing the new book (2020-21), Maria's roles in 2021-22 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 interactions with neurologists, paediatricians, and hospital referrals;
- (ii) preparing client-specific epilepsy action plans for clients, caregivers, and employers;
- (iii) advocacy for members in meetings, via correspondence, or online with medical practitioners, government agencies (e.g. Dept. of Social Services, Work and Income, Kāinga Ora, Dept. of 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 (including via Zoom);
- (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) coordinating and helping to run Epilepsy Club events for members and clients including the bi-monthly Fresca Café socials in Hamilton, Tokoroa, Te Awamutu, and Tauranga;
- (ix) organising activities for 'Epilepsy Awareness Month' in November, which in 2021 included the 'Flying the Flag' project <https://ewct.org.nz/flying-the-flag-for-epilepsy/>;
- (x) communicating with members, clients and supporters through EWCT's Facebook, 'Leading the Way' newsletters, monthly epilepsy research news, and our website (www.ewct.org.nz);
 - our website 'views', 'visitors', and 'sessions/visits' each year show the importance and impact of the site with a substantial increase (by 30 to 37%) in all three categories in 2022 in comparison with 2021
 - averages for the past three financial years are 10,489 visitors, 12,851 sessions/visits, and 23,004 views
 - 80% were new visitors, 20% were returning visitors in 2022
 - increases relate to new seizure alarm content, popularity of student/teacher resources, quiz, first aid posters
- (xi) writing and updating fact sheets for the website (we have 33 fact sheets with 20 activity sheets for children); and
- (xii) designing and preparing material for displays and the websites, such as the posters for first aid.

National-level contributions

The Trust, with the support of administrator and epilepsy advisor, has reviewed and responded to wider concerns at the national level about how its clients are treated.

(1) *PHARMAC changes to epilepsy medication*: EWCT formally objected to PHARMAC's cessation of funding of lamotrigine in favour of a generic substitute (Logem) used in the treatment of epilepsy. EWCT's position was that the switch would be potentially deleterious to many people. We summarised our objections in a letter to Hon. Andrew Little (Minister of Health) on 30 May 2021. We also sent comments to PHARMAC in June 2021 about the cessation of supply of gabapentin and primidone to New Zealand from Oct 2021. All correspondence is on EWCT's website (<https://ewct.org.nz/lamotrigine-funding-switch-our-response-to-the-change/>). We have established good communications with PHARMAC, who contact EWCT about all forthcoming changes.

(2) *Ketogenic dietician*: we are pleased to report success with Waikato Hospital advising us that a ketogenic dietician is being appointed (around August 2022) to help people with intractable epilepsy. This outcome caps a four-year process that began with EWCT's petition to Parliament in October 2018 and numerous efforts, including seeking support from the Ombudsman's Office, since then.

Conclusion I am pleased to conclude by recording that EWCT continues to maintain very high standards in serving the epilepsy community, and that all involved can be proud of their efforts to this end.

David J. Lowe – Chair, EWCT