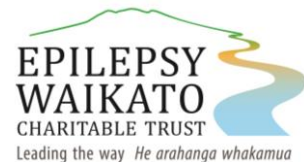


Epilepsy Waikato Charitable Trust AGM

12 September 2023

Chair's annual report



Welcome

I welcome all in attendance at EWCT's 2023 AGM – members, clients, trustees, and guests. I wish to firstly acknowledge and thank all trustees, especially office holders Jill Davies (funding manager, deputy chair), Ashita Bhudia (treasurer), Cyril Markham (alarm sales), and also Maria Lowe (advisor) for their commitment to achieve the aims of the trust. I record with sadness the passing (in late June 2023) of our greatly respected former administrator, Margaret Paine. Margaret gave more than five years of exemplary and selfless service to EWCT. I also acknowledge the retirement of Faith Gibbs in May this year. Faith has spent ~50 years supporting people with epilepsy in the Waikato region, and was a foundation trustee of EWCT and fund raiser from early years until May 2018. I also thank webmaster, Antony Booker, and I remain very grateful to our patron, Hon. Tim Macindoe, for his ongoing support of EWCT.



Photo above shows EWCT Trust Board on 10 December 2022

Overview of EWCT's activities 2022–2023

The main aim of Epilepsy Waikato Charitable Trust (EWCT) is to undertake activities to support people with epilepsy, and their families, friends, and workmates, primarily in the Waikato region but also beyond. To meet this aim, information, advice, advocacy, and support in the past year have been provided by the epilepsy advisor, Maria Lowe, with the Trust's support, as follows:

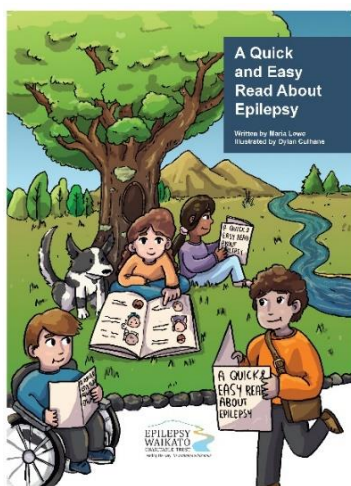
- (i) providing one-on-one advice to people with epilepsy, including new clients, and their families, friends, and workmates, as well as interactions with neurologists, paediatricians, and other medical professionals, and by responding to hospital referrals
- (ii) preparing client-specific epilepsy action plans for clients, caregivers, and employers
- (iii) advocacy for clients in meetings or via correspondence, or online, with medical practitioners, staff of government agencies (e.g., Dept. of Social Services, Work and Income, Kāinga Ora, Dept. of Corrections), social service providers, hospitals, law firms, courts, schools, landlords, and private employers
- (iv) educating through talks and by providing in-service training about epilepsy to a wide range of agencies including social service providers, private companies, retirement homes, and schools
- (v) attending and participating in networking meetings with various community organisations (including via Zoom or equivalent) and developing positive relationships with other NGOs and professional organisations that will further support people with epilepsy and their family members and supporters
- (vi) preparing monthly reports and data for the trustees of EWCT
- (vii) coordinating with EWCT's administrator to help run Epilepsy Club social events for members and clients and supporters including the normally bi-monthly Fresca Café socials in Hamilton, Tokoroa, and other centres, to enable peer-to-peer contact and with other people
- (viii) organising activities for 'Epilepsy Awareness Month' in November
- (ix) communicating with members, clients, and supporters through Facebook, our annual 'Leading the Way' newsletter, epilepsy research articles ('Epilepsy articles'), and EWCT's website (www.ewct.org.nz)
- (x) writing fact sheets for the EWCT website and, in 2023, a new "Easy Read" book about epilepsy (see below)
- (xi) keeping up to date with developments in epilepsy research, such as use of vagal nerve stimulation to help people with intractable epilepsy, and providing such information to EWCT's members and clients
- (xii) designing and preparing materials for displays, including for expos, and for the website
- (xiii) assessing clients to qualify for 'total mobility status' with documentation for the Waikato Regional Council.

National-level activities of EWCT

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

- (i) *Submission: "Accessibility for New Zealanders Bill"*. We made a formal submission to the Parliamentary committee on social services about this bill in October 2022, and Maria Lowe took part in a formal interview with the Social Services Committee on 28 February 2023.
- (ii) *Submission: "Charities Amendment Bill"*. We made a formal submission to Parliament on the review of this bill in December 2022.
- (iii) *Petition*: We launched a (second) petition to Parliament on 25 May 2023 as follows: "That the House of Representatives urge Whatu Ora Health New Zealand to fund vagal nerve stimulation (VNS) therapy for adults with intractable, medication-resistant epilepsy as an adjunct treatment." *Petition reason*: "At least 30% of people living with epilepsy have no seizure control with conventional medications. The VNS therapy could provide relief for many people living with partial-onset and generalised seizures. EWCT wants the House to fully fund the VNS for adults living with intractable epilepsy in New Zealand as an epilepsy treatment option." Total signatures obtained for the petition (open from 25 May–18 June) were 402. The petition, formally presented to Parliament by Jamie Strange (MP for Hamilton East), will be examined by the Parliamentary Health Committee, and a follow up interview with EWCT is anticipated.

New book published by EWCT in February 2023



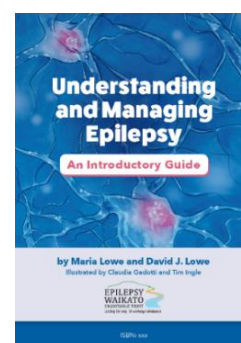
A new book, entitled "***A Quick and Easy Read About Epilepsy***", was published by EWCT in February 2023. Written by Maria Lowe and illustrated by Dylan Culhane, it is the fifth book to be published by EWCT. It is a concise book written for a wide audience of readers ranging from young adults who have recently been diagnosed with epilepsy to those with an intellectual disability, or those who use English as a second language. In the book, Maria explores:

- what epilepsy is
- how it is diagnosed
- how to manage seizures safely, and
- how to live with the condition.

Each sentence is written simply and in large print and is accompanied by quirky illustrations drawn by Dylan Culhane. Although covering a serious topic, this book is a fun read and has a positive message about epilepsy. It has proven popular, a second print run being required in May 2023.

EWCT book reprinted January 2023

A second print run of EWCT's book "***Understanding and Managing Epilepsy – an Introductory Guide***" (by Maria Lowe and David J. Lowe), first published in September 2021, was printed in January 2023. The second printing was at a larger page size (240 x 170 mm) than the original A5 book (210 x 148.5 mm) to make it even easier to read. Hundreds of copies of the first edition have been given to clients, and copies were provided to every library in the Waikato region. Earlier, 100 copies were donated to the Neurology Department, Waikato Hospital (in 2021). EWCT has also published two children's picture books, "Ben's Buddies" and "Ariana and Jack", and a "Seizure Diary".



Epilepsy November awareness month 2022

Maria Lowe organised the daily online documentation of the professional people in our community who form part of our care team (<https://ewct.org.nz/epilepsy-care-team/>) as the 2022 November awareness activity.

EWCT formalised its agency status for Seizure Alert Australia-New Zealand

EWCT is 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.

New trustees, new administrator, life members, hero awards, liability insurance, and EWCT's business plan

- (i) Three new trustees were appointed in 2022–2023: Ashita Bhudia (appointed also as treasurer) (October 2022); David Nicholls (February 2023); and Tracey Morgan (May 2023). David Nicholls was appointed as our new part-time administrator in August, 2023, and so he resigned as a trustee at that time. Foundation trustee, Faith Gibbs, resigned in May 2023 (noted earlier); Bryce Hopkins, trustee from 13 February 2018, resigned in June 2023, serving 5.5 years (plus 18 months as 'adviser to board' from July 2016).
- (ii) Life memberships were awarded to Bruce Hopkins and Jill Davies at the AGM on 13 September 2022, and 'Epilepsy Hero Awards' were made to Darrell Bowler and Ashita Bhudia (of Brinkworth Associates) as well.
- (iii) EWCT finalised new liability insurance for trustees and employees in August 2022 (updated August 2023).
- (iv) EWCT's revised "Business Plan" for 2023-2025 was approved by the Board of Trustees in May 2023.

Additional outputs and other contributions to the epilepsy community

Trustees and administrator

A small core group of volunteers, together with the advisor and part-time administrator, contribute at least 120 hours per week, including preparing for, attending, and contributing to monthly Trust Board meetings (usually 1.5 hours per meeting), keeping track of accounts, developing budgets, approving expenditure, undertaking banking, completing annual financial auditing and providing information about trustee elections or retirements for Charities Services, and minuting proceedings of meetings. The board applies for funding from multiple organisations (an application per month on average), meets with funders, and writes reports for them, prepares documents for the AGM, attends and contributes to network meetings, undertakes staff appraisals, helps run social events, contributes to expos, consults with the Ombudsman on various matters, and prepares occasional media releases. The board, administrator, and supporters also organise and run local fund-raising events including sausage sizzles at Bunnings (normally twice a year), raffles (at expo events), and, since 2022, by commission for selling alarms as agent for Seizure Alert Australia-New Zealand. As well as raising funds, these and other events help provide awareness of epilepsy and EWCT in the community. The preparation and printing of five books by EWCT has been a challenging, time consuming but fulfilling exercise.

Epilepsy advisor

Further to the summary on p.1, we emphasise that the epilepsy advisor (Maria Lowe) spends substantial time with individual clients addressing their specific and often complex needs (individual consultations can be up to three hours or so). She has written many letters of support for her clients to help improve the quality of lives of those living with epilepsy. Maria also provides seizure diaries and explains their usage, which help neurologists fine-tune and enhance their support for our clients. Maria has also written 'action plans' relating specifically to individuals with epilepsy, including school children, to enable carers to help them effectively and safely. She is also a trained and approved assessor for the Waikato Regional Council to evaluate clients to see if they qualify for 'total mobility' status.

Facebook

The Trust's Facebook page is updated daily by the advisor with new and topical information on epilepsy and the social activities of the Epilepsy Club. A regular (normally monthly) article summarising new advances in research about epilepsy is sent to all members and is available on the website (<https://ewct.org.nz/blog/>). As well as referrals from various social service providers and from Waikato Hospital, the website and Facebook site continue to provide the opening for engagement with large numbers of people throughout New Zealand, and beyond, with an interest in epilepsy. The advisor receives requests for help via Facebook or she is advised that the website has led a potential client to EWCT for support.

Sponsors and donors

I thank all donors to EWCT, our funders, and those who have provided in-kind support. Funders/supporters include 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.

David J. Lowe *Chair, EWCT*