

Epilepsy Waikato Charitable Trust AGM, 13th September 2016

Chair's report

I wish to offer a warm welcome to all attendees at the 2016 AGM of EWCT – members, clients, family supporters, trustees, and guests. This AGM marks a significant milestone for EWCT because we have now celebrated our 5th birthday as an organisation. We began in April 2011 and since those difficult early days we can proudly view our growth to become, arguably, the leading epilepsy support provider in the Waikato region because we now employ two epilepsy advisors, Maria Lowe and Margaret McQuillan (see below). Our core roles are to offer support and advocacy to people with epilepsy, and their families and friends, in the Waikato region and beyond, and to help educate and inform the wider public about epilepsy.

Before summarising some of the highlights for the past year, and some exciting developments in the pipeline, I wish to firstly acknowledge our members* who have shown their support and appreciation in many ways to EWCT. Our membership has grown steadily since those early years and now exceeds 200. The ongoing support we get from many members in attending events, providing help in running events, making donations and so on, are really appreciated.

Secondly, I wish to pay tribute to and thank the board of trustees, and advisor Bryce Hopkins who contributes to board meetings, for their commitment to the aims of the trust and for dedicating many hours to ensure the aims are attained. We have a happy, well-functioning board that gets on with the job in an efficient and timely fashion. Much work is undertaken behind the scenes in helping EWCT to thrive. Trustees Ai-Ee Teo (secretary), Faith Gibbs (funding), Cyril Markham (treasurer), and Wade Limpus ('Job Chat') are especially thanked for their very significant work on the trust. I also thank Jill Davies for her work as chair prior to my appointment and subsequently in her role as deputy chair on the board.



Thirdly, special thanks go to our patron, Tim Macindoe, MP for Hamilton West, who continues to strongly support EWCT. As noted at the Epilepsy Hero Awards in July (see below), Tim's enduring advocacy and help for more than 7 years with our epilepsy group has been pivotal to our success.

Tim Macindoe (right) with Lindsay Cumberpatch receiving EWCT's Epilepsy Hero Awards on 9 July 2016.

Fourthly, I acknowledge and sincerely thank all who have donated to EWCT or sponsored our trust's work over the latest financial year. We are supported by donors (private individuals), some of whom make contributions on a regular basis, and numerous funding organisations. The funding organisations and services provide us with significant funds or 'in-kind' support. I mention some of the main ones here: NZ Lotteries Grant Board, Glenice and John Gallagher Foundation, DV Bryant Trust, Community Organisation Grants Scheme (COGS), Skycity Hamilton Community Trust Grants, WEL Energy Trust, Trust Waikato, ANZ New Zealand Staff Foundation, Hamilton City Council Community Funding, and Waikato Print. These and others have together provided the essential funds to run EWCT, and all are acknowledged on our website and on our letterhead documents.

Lastly, and certainly not least, I and board members thank Maria Lowe, our full-time epilepsy advisor, for her hard work in helping many people with epilepsy in our community. Maria (and new advisor Margaret) report to the board each month. Maria's role has encompassed many facets including:

- (i) providing one-on-one advice to people with epilepsy and their families and supporters, including interaction with neurologists and referrals from the Neurology Department of Waikato Hospital;
- (ii) advocacy for members in meetings with medical practitioners, government agencies (e.g. WINZ, Housing NZ, Corrections), and in interview situations (etc);
- (iii) educating through talks (including to schools) about epilepsy, writing fact sheets for the EWCT website, setting up and running displays at expos at Claudelands Event Centre, public events (e.g. Orientation Week at Waikato University; Kaumatua Games), or the Library;
- (iv) helping publish our popular book "Ben's Buddies" and a sequel in preparation (see below);
- (v) running Epilepsy Club events such as the bi-monthly Fresca Café get-togethers and the annual trip;
- (vi) communicating with members and clients and supporters through our website (webmaster Antony Booker of Spindle Media), Facebook site, and newsletters;
- (vii) developing and facilitating courses such as the 'Cooking Classes' with Methodist City Action;
- (viii) developing new support groups in the wider Waikato area and beyond; and
- (ix) organising activities for the Epilepsy Awareness Month (November) including a 'Onesie Walk' around Lake Rotoroa (Hamilton Lake) (photo below).



Looking back: some new developments/activities over the past year

The past financial year has been one not only of 'consolidating' the functioning and practices we have established over the past few years as our branding has become established and our funding, experience and (critically) membership have grown, but also one of development including the appointment of a second epilepsy advisor. The board is confident it can raise the significant funds annually to sustain the employment and work of both advisors as the needs of the epilepsy community in the Waikato region grow. The great work by Faith as funding manager is acknowledged and very much appreciated.

Appointment of second epilepsy advisor (part time)

Such has been the workload carried by Maria that the board appointed a part-time epilepsy advisor, Margaret McQuillan, from 18 July this year. Margaret has been getting to grips with the role for some weeks now and we are thrilled to have her expertise, experience, and commitment to help our members and to help enable EWCT to continue to grow.

Five-year celebratory dinner and Epilepsy Hero Awards

To mark our 5th anniversary, we instituted an "Epilepsy Hero Award" to be made annually to one or two very deserving individuals at the mid-winter 'Christmas' dinner. The inaugural heroes for 2016 were patron Tim Macindoe and Lindsay Cumberpatch, the chief executive of DV Bryant Trust. Framed certificates acknowledging their immeasurable contributions and support for EWCT were presented to Tim and Lindsay (see photo above). In addition, 10 individualised certificates of appreciation were prepared for our 'top ten' funders and these are being presented to the funders when Faith (usually together with Cyril or Ai-Ee) visits the funders to acknowledge and thank them for their support or to discuss the next funding round. The certificates have been warmly received and appreciated.

New support groups

EWCT, through Maria, has established new support groups in Tokoroa, Huntly, and Tauranga. These have evolved through Maria being contacted by people in these localities who see an urgent need to get more information about epilepsy and its impacts on individuals and families/supporters, and to gain benefits from being in a support group. The Tokoroa group especially is growing and its members are to take part in EWCT's trip in November to Taupo.

New auditing to meet requirements of Charities Services

Charities Services undertook a review of the written purpose statements of many organisations including EWCT, and we (and other charities) revised the wording pertaining to the charitable aims of the trust as recorded in the constitution. Our submissions were accepted by the Charities Services and our constitution was amended. Subsequently, the auditing requirements have been changed to include a review of 'service performance' (in addition to the usual 'financial performance') that relates directly to the revised aims in our constitution. I am pleased to report that with the significant help of David Paulussen (of Owen McLeod & Co.), our first audit/review under the new rules passed with flying colours. Thanks are due to Maria for her well-kept monthly statistics, Ai-Ee for extracting administrative data for various time periods, and Cyril for much work in keeping the books on the straight-and-narrow financial path. That the AGM is being held in September this year rather than October as in previous years is partly due to the commitment of David Paulussen and colleagues, and those mentioned above in EWCT, to complete their reviews promptly so that we could hold the AGM within six months of the end of our financial year (31 March).

Epilepsy awareness month

In November 2015, EWCT ran an “Epilepsy Awareness Month” that involved activities to help the community be more aware of epilepsy and the EWCT trust through a set of weekly themes. This month-long event, to occur annually, extends our previous week-long event.

Annual trip

Around 30 members/supporters travelled to Paradise Valley near Rotorua to visit Wingspan, home to the New Zealand falcon (*karearea*) – as seen on \$20 notes – in November 2015. They enjoyed wonderfully compelling talks and flying displays. This year’s trip, scheduled for 12 November, is to comprise a bus trip to the amazing volcanic Taupo area. A volcanologist will be on the trip to answer questions!

Looking ahead: two developments in the coming year

Second book

EWCT is to publish a second book, called “Ariana and Jack”, as a sequel to “Ben’s Buddies”. The bulk of the funding for the book is being provided by the ANZ New Zealand Staff Foundation, who also funded “Ben’s Buddies”. We are extremely fortunate to have such a generous sponsor for what will be another high-quality, benchmark output from EWCT. The new book has been written by award-winning author Sharon Holt (who also wrote “Ben’s Buddies”) and the illustrations are being prepared by Claudia Gadotti, a New Zealand-based Italian artist. Maria has penned informative technical text for the end pages. Dr Ray Harlow has again generously translated the story into te reo Maori. Preparation is well advanced and we anticipate publishing the book early in 2017.

Building fund

Some members may not be aware that we have started a building fund. In our strategic plan in 2015 (due to be revised in 2017), we identified the need to provide a building to accommodate staff and to enable members or clients and supporters to visit the advisors at a one-stop-shop or for groups to receive training. To kick-start the fund we have set up a ‘Trade me’ account to sell items donated to EWCT. Jennifer Goodman kindly facilitates the account on behalf of EWCT. Sales have begun and so we are on the way to getting our building off the ground (literally and figuratively).

Closing remarks

In closing, I think EWCT is in great shape after five years, and all involved can be very pleased and proud of its achievements. I must say I am very proud to chair the trust and I enjoy and appreciate the support of the trustees and members in carrying out the role. I remain very committed to helping make EWCT sustainable and successful in ‘leading the way’ in supporting people with epilepsy.

I also acknowledge the work of Ai-Ee and Cyril in preparing documentation required for the AGM, and trustees and others who have contributed to preparing and serving the refreshments tonight.

(Prof) David Lowe

Chair, EWCT

*EWCT **members** are people who have epilepsy, or people who have an interest or association with epilepsy, and who are recorded on the EWCT database as members; **clients** are people who have received advice and support directly from the epilepsy advisor(s). Clients can also be members.