

Patron's Message for the Epilepsy Waikato Charitable Trust AGM 2023

I am conscious that the past year has been challenging for the Epilepsy Waikato Charitable Trust, tinged with sorrow, and that there are changes in the wind.

I was very sad to hear the news of Margaret Paine's death in June. Margaret was a dedicated and efficient administrator for EWCT. Her strong commitment to serving our trust and Waikato's epilepsy community was very evident in the tributes paid to her at her funeral, which I was privileged to attend with many of our board members.

On a happier note, I was delighted to have the honour of presenting Bryce Hopkins and Jill Davies with EWCT Life Membership awards at the 2022 Trust AGM. Life membership is the highest honour any organisation can bestow upon its members, and few could be more deserving than Bryce and Jill, both of whom have served EWCT with such devotion and success over many years.

At that meeting it was also my pleasure to present EWCT Hero Awards to Ashita and Darrell (of Brinkworth Associates) in grateful recognition of their considerable help with accounting and treasurer duties. I was delighted to hear that Ashita subsequently accepted an invitation to join the board as a trustee.

Board members considered important strategic planning matters at a special meeting at the home of our Chairperson and Epilepsy Advisor last December. I was pleased to chair some of those discussions. (Our Advisor demonstrated that when she finishes in her current role, she could have a stellar career in catering!)

All trusts need to refresh board membership on a regular basis, and be ready for staff changes at any time. Accordingly, planning for the future under fresh personnel was a major focus of the discussion, and I commend our Chairperson and his team for their focus on ensuring the sustainability of the important work the EWCT does in supporting those who live with epilepsy in our region. Many current board members have served since EWCT's inception, and the previous EW organisation for many years before that, and I am full of admiration and gratitude for their commitment.

I am pleased to acknowledge that Waikato Hospital is at last developing a ketogenic dietician service for clients with intractable epilepsy, although when that service will commence is not yet known. It has been exceedingly frustrating that 4 years have elapsed since a Parliamentary Select Committee recommended this service in support of EWCT's Ketogenic Diet petition (presented nearly 5 years ago in October 2018). There is compelling international evidence of the ketogenic diet's effectiveness in alleviating the impacts of seizures for many of those who live with the condition, and the service has been available elsewhere in New Zealand for some time.

Nevertheless, I commend Maria, David and the board for again championing the needs of those who live with intractable epilepsy through their recent petition calling upon MPs to urge Te Whatu Ora Health New Zealand to fund vagal nerve stimulation (VNS) therapy for adults with intractable, medication-resistant epilepsy as an adjunct treatment. It was tabled in Parliament in July, leaving little time for it to be dealt with before the House rises for this year's General Election, so it is to be hoped it will be considered quickly and favourably by members of the incoming Parliament next year.

As Patron since EWCT's inception, and an advocate for the interests of those who live with epilepsy in Waikato since the challenges the former regional branch faced approximately 15 years ago came to light, I have enjoyed a close relationship with EWCT and have huge admiration for all that the current and former board members and staff have done to meet the needs of the community they serve. Therefore, I extend renewed thanks to David and Maria Lowe, and all EWCT trustees, for their dedication and hard work over the past year, and to all of EWCT's sponsors, supporters and donors for your generosity and backing that enables our trust to operate as it does, providing a high level of service to make an enormous difference to many. Bless you all!

Warmest regards,

Tim Macindoe, Patron, EWCT