

Policy on the promotion of treatments for migraine disease

1. Background

As New Zealand's peak advocacy group for migraine disease, Migraine Foundation Aotearoa New Zealand (MFANZ) is approached by individuals, groups and services who have an interest in gaining access to our community through our social media, website or other communications, including for the purpose of communicating Treatments, for the purposes of Research and for other similar purposes.

This policy aligns with the following MFANZ strategic objectives:

- a. **Trusted source of robust, relevant, evidence-based and NZ-specific information**
- b. **Respected, national leadership in advocacy for migraine disease in NZ**
- c. **Connect and support people living with migraine disease**

2. Purpose

The purpose of this policy is to assist MFANZ personnel to deal with approaches from third parties who ask us to:

- 1.1. Promote Treatments for migraine disease to our community, or
- 1.2. Connect them with our community for the purposes of providing information on a Treatment or making the community aware of a Treatment.

3. Definitions

'**Promotion**' means posting about the treatment on social media, referring to the treatment on the MFANZ website, newsletter or other communications in a way that could imply MFANZ recommends, endorses or supports the treatment.

Definitions (cont.)

‘Reasonable Standard of Evidence’ for a Treatment means:

- a. acceptance of the Treatment by other reputable migraine patient organisations (e.g. Migraine Trust, Migraine and Headache Australia, American Migraine Foundation), or
- b. a recommendation within a well-researched and reputable guideline for migraine management (e.g. from the American Headache Society), and for a Treatment that is:
 - i. a pharmaceutical, that the pharmaceutical has been the subject of a randomised controlled clinical trial (RCT), or
 - ii. a device, that the device has been approved by the FDA, Medsafe or an equivalent organisation in a comparable jurisdiction.

‘Treatment’ means any pharmaceutical or non-pharmaceutical treatment, intervention, device, service, plan or any other approach that has a stated intent to treat migraine disease, either acute attacks and/or to prevent attacks.

4. Guiding principles

MFANZ aims to provide robust, relevant, evidence-based information to its community.

MFANZ is also aware that members of its community will come across “cure-alls”, miracle cures and alternative therapies through sources other than MFANZ, and aims to raise awareness of the limitations of such Treatments so that members of our communities can avoid quackery and approach all Treatments fully informed.

This policy seeks to balance our commitment to provide robust, relevant and evidence-based information with awareness raising across all Treatments to mitigate the risk of vulnerable individuals falling for harmful or sham treatments while protecting MFANZ’s reputation as the respected, national leader for migraine in Aotearoa New Zealand.

5. Procedures

- 5.1 MFANZ will decline to Promote any migraine Treatment that:
- i. in the reasonable opinion of the MFANZ Committee or MFANZ's management, may cause harm
 - ii. includes any suggestion or claim to be a 'cure' for migraine
 - iii. contradicts or is inconsistent with the current medical understanding of migraine as a neurological disease (that can be worsened by social, environmental and personal factors; that can be managed or go into remission; but is not curable), or
 - iv. does not meet a Reasonable Standard of Evidence for its effectiveness and safety.
- 5.2 When considering the promotion of a migraine Treatment, MFANZ personnel must weigh up the risk of damage to MFANZ's reputation if a Treatment is promoted that may cause harm to a member of the migraine community, including financial harm from investing in a treatment that has no or unproven efficacy.
- 5.3 Any approach to promote a migraine Treatment that has commercial value should be discussed with the MFANZ Board. The Board has the final say on how to respond to such approaches.
- 5.4 MFANZ is under no obligation to promote any migraine Treatment, and will not put itself into a position where it could become obliged to promote any Treatment or Research.
- 5.5 This policy may also be relevant when considering requests for promotion of Research into migraine treatments or migraine disease. For such requests, MFANZ personnel must also consider:
- i. The reputation and status of the research team (is this research likely to be completed and results published), and
 - ii. Potential benefit to the migraine community (e.g. will the research provide access to treatments that are not otherwise readily available in NZ) and potential harms. Priority should be given to research that may have direct benefit to people with migraine in Aotearoa New Zealand.
 - iii. The quality and rigour of the research proposal and methods.