

CHANGE TO CONSTITUTION OF FRAGILE X ASSOCIATION OF AUSTRALIA INC 2023

INTRODUCTION

1. The charity regulator (ACNC) recommended that the Fragile X Association of Australia (FXAA) change its charity type from 'Public Benevolent Institution' (PBI), conferred in 2002, to 'Health Promotion Charity' (HPC).

2. The Board has examined the difference between these two charity types and is satisfied that the Deductible Gift Recipient (DGR) status of FXAA will not be affected, nor will there be any change to FXAA's current tax concessions in relation to income or other taxes. When the 'charitable objects' of FXAA were formulated (2002) the HPC charity type was not in the system. When FXAA was established the only category of charity with DGR status available to the organisation was PBI, and care had been taken by the Board that the organisation's charitable objects met the criteria for that category. In particular, the charitable object of the provision of clinics can no longer be said to be a principal activity of FXAA, as FXAA does not provide clinics directly.

3. Therefore the category HPC is a better fit for all of the objects and work of FXAA. As a consequence, it was appropriate to also review the Constitution of FXAA. The changes considered by the Board included an update of the charitable objects of FXAA and an update to certain operational clauses in line with current ACNC, ATO and NSW Department of Fair Trading regulations and guidance.

4. At the FXAA Board meeting on 28 October 2024, the Board resolved to submit the following changes to the FXAA Constitution to the next Annual General Meeting on 1 December 2024.

SUMMARY OF CHANGES PROPOSED:

1. Replace references to Fragile X syndrome with *Fragile X-associated conditions*, in order to recognise the range of conditions associated with changes to the FMR1 gene ie. Fragile X syndrome and Fragile X premutation associated conditions.
2. Change a reference from Fragile X-associated premature ovarian insufficiency to *Fragile X-associated primary ovarian insufficiency*.
3. Update the *Charitable Objects* of the Association to:
 - a. remove reference to multidisciplinary clinics established, managed or provided by the Association
 - b. include reference to the means of support provided for individuals with a Fragile X-associated condition (including counselling, information, referrals, peer connections)
 - c. elaborate on existing charitable objects
4. Provide for membership for any professional whose work or interest relates to Fragile X-associated conditions.
5. Specify that the Association operates as a *Non-profit organisation*.
6. Specify that the Association will take out and maintain appropriate *insurance coverage*.
7. Update the *Dissolution* criteria and processes for the Association to include revocation of Deductible Gift Recipient status.

FXAA Constitution 2023 can be viewed here: <https://bit.ly/FXAAConstitution2023>

Proposed Constitution 2024 can be viewed here: https://bit.ly/FXAAConstitution2024_proposed

DETAILED CHANGES PROPOSED

NOTICE OF RESOLUTION

To give effect to the changes proposed by the Board, a Special Resolution is proposed to amend the Constitution 2024 as follows:

DEFINITIONS

Clause 2 be amended to read as follows: -

"Fragile X-associated condition" means a genetic condition related to the mutation of the FMR1 gene on the X chromosome, including Fragile X syndrome and Fragile X premutation-associated conditions.

"person with a Fragile X-associated condition" means a person having any condition associated with Fragile X, including Fragile X syndrome, Fragile X pre-mutation, and Fragile X Premutation Associated Conditions (FXPAC) including but not restricted to Fragile X-associated primary ovarian insufficiency (FXPOI) and Fragile X-associated tremor/ataxia syndrome (FXTAS).

OBJECTS OF THE ASSOCIATION

Clause 3 to be amended as follows:

The objects of the Association are to promote the detection, treatment and control of Fragile X-associated conditions through means including:

- a) Providing support to individuals with a Fragile X-associated condition and their family members/carers, through means including counselling, information, referrals, and peer connections.
- b) Raising public awareness of Fragile X-associated conditions.
- c) Promoting education in relation to Fragile X-associated conditions through educational forums, meetings, conferences, and producing publications.
- d) Supporting diagnosis, intervention and other programs in relation to Fragile X-associated conditions.
- e) Supporting research into Fragile X-associated conditions.
- f) Advising and lobbying government and other agencies on public policy matters including testing, screening, diagnosis, management and supports related to Fragile X-associated conditions.

MEMBERSHIP

[Members] Clause 6 be amended to read as follows:

The Board may admit as a Member any person over 18 years of age whom it considers has a concern or involvement with Fragile X-associated conditions including as:

- a person with a Fragile X-associated condition,
- a parent, guardian, carer or relative of a person with a Fragile X-associated condition,
- a health practitioner or other professional whose work or interest relates to Fragile X-associated conditions,
- a person with a demonstrated commitment to advancing the objects of the Association,
- an organisation with an interest in Fragile X-associated conditions which nominates a representative to act on its behalf from time to time.

FINANCIAL MATTERS

[Funds] Clause 31 be amended to read as follows:

[Title] 31. Funds and Non-profit Status

(g) The Association shall take out and maintain insurance as appropriate for the Association's assets and liabilities.

DISSOLUTION

[Dissolution] Clause 34 to be amended to read as follows:

34. Winding up or Revocation of DGR Endorsement

(a) The Association shall be dissolved upon the passing of a vote of a special resolution of Members present at a Special General Meeting convened to consider such question.

(b) If the Association is wound up or its endorsement as a deductible gift recipient is revoked (whichever occurs first), any surplus of the following assets shall be transferred to another organisation with similar objects, which is charitable at law, to which income tax deductible gifts can be made:

- gifts of money or property for the principal purpose of the organisation
 - contributions made in relation to an eligible fundraising event held for the principal purpose of the organisation
 - money received by the organisation because of such gifts and contributions.
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