

TRUST DEED of THE FRAGILE X NEW ZEALAND TRUST

1. **Name:** The name of the Trust shall be the Fragile X New Zealand Trust.

2. **Mission Statement:**

To support individuals, families and communities affected by fragile X syndrome and fragile X-associated disorders. To promote awareness and understanding of these disorders.

3. **Objectives:**

3.1 Support and Well-being

- Preserve, foster and promote the rights, interests and well-being of those persons in New Zealand with or in any way affected by fragile X syndrome and fragile X-associated disorders.
- Develop and maintain a national support network.
- Assist with advocacy on health, education and quality of life issues by providing individual support and/or collective lobbying as required.

3.2 Information & Communication

- To develop and maintain a collection (electronic and/or hardcopy) of up-to-date information including:
 - Research and treatment
 - Interventions and education
 - Positive community living strategies
- Utilise appropriate communication systems for the purpose of regular information sharing within the support network.

3.3 Research and Treatment

- Maintain, enhance and develop relationships with related national and international organisations
- Attend relevant events to gather new information for our community

3.4 Education and Awareness

- Promote public awareness and foster public understanding
- Work with Government agencies to build awareness and support within the health and education sectors
- Creation of education programmes

We are guided by the United Nations Convention on the Rights of Persons with Disabilities, Whāia Te Ao Mārama: the Māori Disability Action Plan, and Faiva Ora: the National Pasifika Disability Plan.

4. Powers:

To obtain its objectives, the Trust shall have all discretion and powers available to it under the Charitable Trusts Act 1957 (herein referred to as the Act) and subsequent legislation and shall have the following powers and discretions:

- To purchase, lease, rent or hire any property or equipment which will assist the Trust in the attainment of its objectives.
- To sell or dispose of any property in its possession, or to maintain, repair or improve any property it holds, and to make provision for the depreciation or replacement of property, as it sees fit.
- To enter into agreements, contracts or arrangements with other persons or entities to achieve its objectives, including the employment or contracting of individuals or entities to carry out any of its tasks or responsibilities.
- To seek legal, financial, business, medical, research or other advice from suitably qualified persons or entities.
- To seek donations grants and gifts to the work of the Trust, or to borrow money for its purposes, or to make charges for its services, other than for services to affected people or their families.
- To make grants to individuals or organisations engaged in research to improve knowledge of the causes and treatment of Fragile X Syndrome, and to improve the care and support of affected people and their families.
- To do all things incidental to or conclusive to the attainment of the objectives of the Trust and to exercise the powers of the Trust.

5. Board of Trustees:

Management of the Trust shall be the responsibility of the Board of Trustees and they shall carry out the functions necessary for the attainment of Trust objectives in accordance with the rules of this deed and the Act. The board may appoint trustees to carry out specific roles and may also appoint officers, external of the board, to assist them in this process.

The board shall consist of no fewer than five trustees, who may appoint additional or replacement trustees based on a majority decision of the trustees. If the number of trustees is reduced below five, the remaining trustees shall have the power to appoint additional trustees and to continue to exercise the powers of the board until the new

trustees are appointed. Appointment of replacement trustees shall be completed as soon as practicable.

Trustees may resign by written notice to the board. The board, by unanimous decision of all other trustees, may require the resignation of a trustee who acts in any way contrary to the interests of the Trust, provided that the trustee shall first be given an opportunity to be heard, and the board shall be guided by natural justice in its decision.

6. Meetings:

Meetings of the board shall be held at the discretion of the majority of trustees or when called by the Chairperson, and shall include one annual meeting to receive financial reports, and at least one other meeting in each year. The annual meeting may be advertised via e-mail bulletin and/or newsletter so as to allow individuals and families within the support network to attend.

By agreement among the trustees, meetings may be held in person, by phone conference, or by other means of communication available to the board. Notice of meetings may be given in writing or directly communicated to trustees by phone, electronic mail or in person. A quorum for meetings shall be three trustees, or as determined by the Trust at an annual meeting.

7. Trust Fund:

All funds and properties of whatever nature or kind presently held by the Trust for the purpose of the objects mentioned above and such further or other funds and property of whatsoever nature or kind as may be possessed by the Trust in the future shall become the Trust Fund.

8. Payments of the Trust:

The income and property of the Trust, from wherever derived, shall be applied towards the promotion and attainment of Trust objectives. This will not prevent payment of reasonable remuneration or expenses to any person for any services performed by them for the board, and with the agreement of the board. Any such income paid shall be reasonable and relative to that which would be paid in an arm's length transaction (being the open market value).

All payments, other than petty cash payments, shall be by cheque and all cheques shall be signed by two trustees, one of which will be the Treasurer.

9. Accounting and Audit:

The Trust shall keep accurate accounting records of the affairs, assets and transactions of the Trust.

A limited review or audit of the Trust's accounts shall be undertaken annually by a suitably qualified person.

10. Indemnity of the Board of Trustees:

No trustees shall be liable for any act, receipts, neglect or default of any other member of the board of the Trust or for any loss occasioned by an error of judgement or oversight on their part or for any other loss, damage or misfortune whatever which shall happen in the execution in the duties of their office or in relation thereto unless the same happened through their own wilful dishonesty.

The trustees shall not be liable for breach of Trust in any matter affecting the administration of the affairs of the Trust or the Trust Fund where they have first obtained recognised professional advice in respect of such matter and acted prudently in the best interests of the Trust, and the board shall indemnify and save harmless each of them the trustees from all costs, claims, actions, suits and proceedings against them personally so long as they shall have so acted.

11. Alteration of Rules:

Subject to the provisions of the Act, these rules or any of them may be altered, added to or rescinded by a resolution in that behalf passed by a majority of not less than two thirds of the trustees who vote in person or by proxy at a meeting of which notice specifying the intention to propose the resolution has been duly given, provided that such alteration is not inconsistent with the charitable objects of the Trust. No addition to or alteration of the pecuniary profit clause or the liquidation clause shall be made without the Inland Revenue Department's approval.

12. Registered Office:

In accordance with the Act, the Trust shall have a registered office to which all communications may be addressed and notice of the situation of that office and of any change shall be given to the registrar as provided by that Act.

13. Liquidation:

The Trust may be wound up or dissolved by resolution of two thirds of trustees voting at an annual meeting for which notice of the meeting and the proposed resolution has been given. The resolution must be confirmed at a subsequent meeting of the Trust for which 28 days notice of the meeting and the resolution has been given.

All surplus assets of the Trust after payment of all costs, debts and liabilities shall be disposed of to any Trust or Trusts or to any society or societies which exist or exists in New Zealand exclusively or principally for similar charitable purposes as the resolution

directs, or failing such direction then as the Attorney General may direct or as the High Court of New Zealand may (on due application) determine.

14. Acknowledgement by the Trustees

1. The Trustees acknowledge that on the signing of this Deed they will hold the Trust fund on Trust for the purposes set out in the objects of this deed.
2. The Trust fund will also include all money and property received or acquired by the Trustees for the purposes of these trusts at any time after the signing of this Deed.
3. The Trustees will have the powers set out in this Trust Deed.
4. The Trustees will follow the rules set out in this Trust Deed.