

Dated:

29 August,

2020

Varied Trust Deed of The Angelman Network

CC No: 46746

Ursula Moira Christel, Elizabeth Ann Becker, Nicola Mary Eley and Lisa Jean Carey
(“the Trustees”)

The Angelman Network Varied Trust Deed

THIS DEED made on the 4 May 2011 and varied by deed dated 29 August, 2020

Parties:

Ursula Moira Christel of Warkworth and **Nicola Mary Eley** of Auckland and **Elizabeth Ann Becker** of Cambridge and **Lisa Jean Carey** of Dunedin ("The Trustees")

INTRODUCTION

- A. The Angelman Network Trust ("the Trust") was created by deed dated 4 May 2011 ("the Trust Deed"). The Trustees are the current Trustees of the Trust.
- B. The Trustees have resolved to revise and vary the Trust Deed as per the Deed of Variation dated 29/08/2020.
- C. The structure of the Trust remains the same: The Trust will be administered by the Board which shall be comprised of six (6) Trustees. Trustees shall be appointed and hold office as Trustees in accordance with the provisions of this varied deed.
- D. The signatories to this Deed will be the current Trustees of The Angelman Network.
- E. This deed is to be known as the "Varied Trust Deed" and replaces the Trust Deed and should be read in its entirety as the rules of the Trust.

1. TE INGOA / NAME

- 1.1 The name of the Trust is THE ANGELMAN NETWORK, hereafter called 'the Trust'.

2. MĀTĀPONO / PRINCIPLES

- 2.1 The Trust is committed, in attaining its purposes, to:
 - (a) respecting and implementing the dual heritage of the partners of Te Tiriti o Waitangi (the Treaty of Waitangi);
 - (b) respecting the cultural diversity of people and encourage people from all nationalities to utilize the Trust's facilities and services.
- 2.2 Our principles:
 - (a) The Angelman Network is a NZ support network with a global web presence, which aims to enhance the lives of people with Angelman Syndrome in New Zealand. We aim to be an inclusive, collaborative, and transparent organisation that operates with integrity and respect for all cultures.
- 2.3 O motor kitenga/ Our Vision:

- (a) The Angelman Network's vision is that people with Angelman syndrome will be included, heard, and valued as unique individuals and contributing members of their community. We encourage a person-centred approach based on the United Nations Convention on the Rights of Persons with Disabilities.
- (b) That people with Angelman syndrome are / Te tangata mau i te mate AS ka:
 - (i) accepted and acknowledged as unique individuals / whakaaetia, manakotia hoki kia u ki to rátou mana ake.
 - (ii) given access to a full language system (AAC) so that their voices can be heard /kia whiwhi ai ki nga ara reo kia rongohia ai o ratou reo e te katoa ma roto i te àpítitanga me etahi atu whakamòhiotanga.
 - (iii) valued as contributing members of their community / kia whai hua rátou hei tángata tákoha nó tó rátou hápori.

3. **WHĀINGA / PURPOSE**

3.1 The purposes of the Trust are to apply the capital and income of the Trust to any valid charitable purpose within New Zealand and overseas; these will be selected by the Board, and must support the following charitable purposes:

- (a) To connect families affected by Angelman Syndrome across New Zealand, by improving contact, information sharing and support.
- (b) To provide up-to-date information on Angelman Syndrome for families and professionals; and to support the education of families, clinicians, professionals, and others involved in the care and support of those with Angelman syndrome
- (c) To raise awareness for Angelman Syndrome within the wider community, across New Zealand
- (d) To network with key support, advocacy, and research agencies, both nationally and internationally, to promote common interests and support common causes.
- (e) To support and promote appropriate medical, genetic, and other specialist services in New Zealand, to meet the needs of those with Angelman syndrome, and their families.
- (f) To support and promote the collective rights of people who have Angelman syndrome, and the rights of their full-time family/whanau carers
- (g) To raise funds and accrue assets to achieve these aims.

4. **TARI / REGISTERED OFFICE**

- 4.1 The registered office of the Trust shall be 21 Wilson Road, Warkworth, Auckland, 0981 or such other places as the Trustees shall resolve from time to time.

5. TE RUNANGA WHAKAHAERE / THE BOARD OF TRUSTEES

- 5.1 The Trust will be administered by a Board of Trustees consisting of not less than two (2) persons and not more than six (6) persons, to be known as the Trustees.
- 5.2 Trustees are to be elected by the Board at an Annual General Meeting ("AGM") and whenever a vacancy occurs. Trustees are elected at the AGM this must be done by a two-third (2/3) majority vote of the Trustees. The Trustees will elect among themselves a Chairperson, Secretary and Treasurer.
- 5.3 If there are less than 2 Trustees at any time the remaining Trustee shall have the power of appointment to elect a Trustee but the remaining Trustee shall not continue to exercise any other powers of the Board until new Trustees are appointed.
- 5.4 Nomination for a position as a Trustee shall be by way of notice of nomination by a Trustee in writing, endorsed with the consent of the nominee and given to the Secretary not less than 24 hours before the AGM. If there are insufficient nominations to fill the vacant Trustee positions, oral nominations may be received at the AGM provided that no member shall be elected who has not consented to being nominated.
- 5.5 Subject to clause 5.2 the Board will have the power to fill any vacancy that arises in the Board or to appoint any additional trustees.
- 5.6 The term of office for each Trustee is two (2) years. Trustees shall be eligible for re-election up to a total of two (2) consecutive terms (four years). This limit may be extended in exceptional circumstances.
- 5.7 All Trustees must stand down for one year after completing a four (4) year term, becoming eligible for re-election, except as allowed under clause 5.6
- 5.8 For continuity, the Board will attempt to ensure that no more than half the Trustees stand down at each election.
- 5.9 If a Trustee, including an office-bearer, does not attend three (3) consecutive meetings of the Board without leave of absence that member may, at the discretion and on decision of the Board, be removed as a Trustee, and/or from any office of the Trust which she or he holds.
- 5.10 A person will immediately cease to be a Trustee when she or he resigns in writing, dies, is declared bankrupt or is found to be a mentally disordered person within the meaning of the Mental Health (Compulsory Assessment and Treatment) Act 1992 or subsequent enactment.
- 5.11 The Board has the power of removal of a Trustee by a two-thirds (2/3) majority of votes to terminate a person's position as a Trustee, if it believes that such action is in the best interests of the Trust.
- 5.12 The Board may continue to act notwithstanding any vacancy, but if their number is reduced below minimum number of trustees as stated in this deed, the continuing

trustee/s may act for the purpose of increasing the number of trustees to that minimum but for no other purpose.

6. NGA HUI O TE RUNANGA WHAKAHAERE/ MEETINGS OF THE BOARD

6.1 The procedure for Board meetings will be as follows:

- (a) A quorum will be at least half of its members.
- (b) All motions/questions will be decided by consensus. If a consensus cannot be reached then a decision will be made by a majority vote by show of hands, unless otherwise determined by the Board.
- (c) If the voting is tied, the motion will be lost.
- (d) In the absence of the Chairperson, the Board will elect a person to chair the meeting from among the Trustees present.

6.2 The Board will meet at least four (4) times every year. Meetings may be held in person or by any other means of communicating as decided on by the Board from time to time. The Secretary will ensure that all members of the Board are notified of the meeting in writing, at least a week before the date of the meeting.

6.3 The Secretary will ensure that a minute book is maintained which is available to any member of the Trust and which, for each meeting of the Board, records

- (a) the names of those present;
- (b) all motions passed by the Board; and
- (c) any other matters discussed at the meeting.

7. TAKETAKE/ POWERS

7.1 In addition to the powers provided by the general law of New Zealand or contained in the Trustee Act 1956, the powers which the Board may exercise in order to carry out its charitable purposes are as follows:

- (a) to use the funds of the Trust as the Board thinks necessary or expedient in payment of the costs and expenses of the Trust, including the employment and dismissal of professional advisors, agents, officers and staff, according to principles of good employment and the Employment Relations Act 2000 or any subsequent enactment;
- (b) to purchase, take on, lease or in exchange or hire or otherwise, acquire any real or personal property and any rights or privileges which the Board thinks necessary or expedient in order to attain the purpose of the Trust and to sell, exchange, let, bail or lease, with or without option of purchase or, in any other manner, dispose of such property, rights or privileges;

- (c) to invest surplus funds in any way permitted by law for the investment of Charitable Trust funds and upon such terms as the Board thinks fit;
- (d) to borrow or raise money from time to time with or without security and upon such terms as to priority or otherwise as the Board thinks fit; and
- (e) to do all things as may from time to time be necessary or desirable to enable the Board to give effect to and attain the charitable purposes of the Trust.

8. KO NGA RAWA HEI PAINGA MO TE IWI/ INCOME, BENEFIT OR ADVANTAGE TO BE APPLIED TO CHARITABLE PURPOSES

- 8.1 Any income, benefit or advantage will be applied to the charitable purposes of the Trust.
- 8.2 No trustee or members of the Trust or any person associated with a trustee shall participate in or materially influence any decision made by the trustees in respect of any payment to or on behalf of that trustee or associated person of any income, benefit or advantage whatsoever.
 - (a) Any such income paid shall be reasonable and must be made at market rates or less than market rates.
 - (b) The provision and effect of this clause shall not be removed from this deed and shall be implied into any document replacing this deed of trust.

9. TURU TAKETAKE/ POWER TO DELEGATE

- 9.1 The board may from time to time appoint any committee and may delegate any of its powers and duties to any such committee or to any person. The committee or person may without confirmation by the Board exercise or perform the delegated powers or duties in the same way and with the same effect as the Board could itself have done.
- 9.2 Any committee or person to whom the Board has delegated powers or duties will be bound by the terms of the Trust and any terms or conditions of the delegation set by the Board.
- 9.3 The Board will be able to revoke such delegation at will, and no such delegation will prevent the exercise of any power or the performance of any duty by the Board.
- 9.4 It will not be necessary for any person who is appointed to be a member of any such committee, or to whom such delegation is made, to be a Trustee.

10. PŪTEA/ FINANCIAL ARRANGEMENTS

- 10.1 The financial year of the Trust will be from 1 April to 31 March.
- 10.2 At the first meeting of the Board in each financial year, the Board will decide by resolution the following:

- (a) How money will be received by the Trust;
- (b) Who will be entitled to produce receipts;
- (c) What bank accounts will operate for the ensuing year, including the purposes of and access to accounts;
- (d) Who will be allowed to authorize transactions, the production of cheques and the names of cheque signatories; and
- (e) The policy concerning the investment of money by the Trust, including what type of investment will be permitted.

10.3 The Treasurer will ensure that true and fair accounts are kept of all money received and expended by the Trust.

10.4 If deemed necessary, the Board may arrange for the accounts of the Trust for that financial year to be audited by an accountant appointed for that purpose.

11. TE TOHE TAKETAKE/ COMMON SEAL

11.1 The Common Seal of the Board, following its incorporation, will be kept in the custody and control of the Secretary, or such other officer appointed by the Board.

11.2 When required, the Common Seal will be affixed to any document following a resolution of the Board and will be signed by the Chairperson (or a trustee acting as the Chair) and one other trustee appointed by the Board.

12. TAKAWAENGA/ MEDIATION & ARBITRATION

12.1 Any dispute arising out of or relating to this deed may be referred to mediation, a non-binding dispute resolution process in which an independent mediator facilitates negotiation between parties.

12.2 Mediation may be initiated by either party writing to the other party and identifying the dispute which is being suggested for mediation. The other party will either agree to proceed with mediation or agree to attend a preliminary meeting with the mediator to discuss whether mediation would be helpful in the circumstances.

12.3 The parties will agree on a suitable person to act as mediator or will ask the Arbitrators' and Mediators' Institute of New Zealand Inc. to appoint a mediator. The mediation will be in accordance with the Mediation Protocol of the Arbitrators' and Mediators' institute of New Zealand Inc.

13. TAUNAHA/ TRUSTEE LIABILITY

13.1 It is declared that:

- (a) The Trustees are chargeable respectively only in respect of the money and securities they actually receive, or which, but for their own acts, omissions,

neglects, or defaults they would have received, notwithstanding their signing any receipt for the sake of conformity; and

- (b) They are each answerable and responsible respectively only for their own acts, receipts, omissions, neglects and defaults and not for those of each other, or of any banker, broker, auctioneers, or other person with whom, or into whose hands, any Trust money or security is properly deposited or has come;
- (c) No Trustees shall be liable personally for the maintenance, repair, or insurance of any charges on such property;
- (d) No Trustees hereof shall be liable for any loss arising from any cause whatsoever including a breach of the duties imposed by Section 13B and/or Section 13C Trustees Act 1956 (as enacted by the Trustee Amendment Act 1988) (or any statutory replacement or equivalent) unless such loss is attributable:
 - (i) To his or her own dishonesty; or
 - (ii) To the wilful commission by him or her of an act known by him/her
 - (iii) to be a breach of Trust.
 - (iv) And pursuant to Section 13D of the Trustees Act 1956 it is intended by this clause that the duties imposed by Section 13B and 13C of the Trustees Act 1956 shall not apply to any Trustee hereof.
- (e) No Trustees shall be bound to take any proceedings against a co-Trustee for any breach or alleged breach of Trust committed by that co-Trustee.
- (f) Notwithstanding the procedure or otherwise of retaining assets in the Trust Fund no Trustee shall be liable for any loss suffered by the Trust Fund by reason of the Trustees retaining any asset forming part of the Trust Fund.
- (g) The Trustees shall from time to time and at all times be indemnified by and out of the Trust property from and against all costs, charges, losses, damages, and expenses sustained or incurred by them or in or about the execution and discharge of their office or in or about any claim, demand, action, proceeding or defence at law or in equity in which they may be joined as a party.

14. TE TUKU TOENGA RAWA/DISPOSITION OF SURPLUS ASSETS

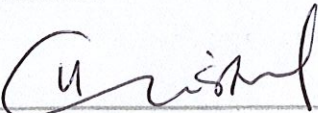
- 14.1 On the winding up of the Trust, or on its dissolution by the Registrar, all surplus assets, after the payment of costs, debts and liabilities will be given to other charitable organisation/s within New Zealand as the Board will decide.
- 14.2 If the Trust is unable to make such a decision, the surplus assets will be disposed of in accordance with the directions of the High Court pursuant to section 27 of the Charitable Trusts Act 1957 or subsequent enactment.

15. **WHAKAREREKĒTANGA TURE/ALTERATION OF THIS DEED**

- 15.1 The Trustees may by consensus or pursuant to a motion decided by a majority of votes, by supplemental deed make alterations or additions to the terms and provisions of this deed provided that no such alteration or addition will detract from the exclusively charitable nature of the trust or result in the distribution of its assets on winding up or dissolution for any purpose that is not exclusively charitable.
- 15.2 Any alteration or addition must be recorded in writing either in a supplemental deed or a trustees' resolution signed by all trustees.

IN WITNESS OF WHICH this Deed has been executed:

SIGNED by Ursula Moira Christel as one
of the Trustees in the presence of:


Ursula Moira Christel

Witness:



Signature of witness

JAEWOO LEE

Full name of witness


SUPPORT WORKER

Occupation of witness

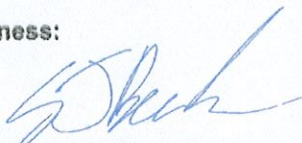
4 BEVERLEY RD. STANMORE BAY

Address of witness AUCKLAND

SIGNED by Elizabeth Ann Becker as one
of the Trustees in the presence of:


Elizabeth Ann Becker

Witness:



Signature of witness

Scott Jay Becker

Full name of witness

Land Surveyor

Occupation of witness

11 Fergusson Gully Rd, Karapiro

Address of witness

SIGNED by Nicola Mary Eley as one of the
Trustees in the presence of:

Nicola Mary Eley
Nicola Mary Eley

Witness:

Sarah Jones

Signature of witness

Sarah Jones

Full name of witness

Associate Principal

Occupation of witness

210 Melling Street, Glen Innes, Auckland, 1072.

Address of witness

SIGNED by Lisa Jean Carey as one of the
Trustees in the presence of:

LJ Carey
Lisa Jean Carey

Witness:

Nathan Webb

Signature of witness

Nathan Webb

Full name of witness

Scaffolder

Occupation of witness

2a Christie St, Dunedin

Address of witness

NOTE: The Trust Deed must be certified as a correct copy by one of the trustees, or a member of the committee or governing body of the society with the following statement:

"I hereby certify that this is a correct copy of the trust deed or rules of The Angelman Network".

Full Name: URSULA MOIRA CHRISTEL

Signed: [Signature]

Date: 29 August 2020