

"H"

TRUST DEED

THIS TRUST DEED is made on the 22 January 2013

BETWEEN

Francis Harper of 29 Prince Albert Street, Mosman, 20 88 ("the Founder") of the one part

DEBRA AUSTRALIA LIMITED of 29 Illing Road Rossvale QLD 4356 ("the Original Trustees") of the other part

WHEREAS

- A. The Founder, being concerned at the extent of the problems caused within the community of the Commonwealth of Australia by the disease known as Epidermolysis Bullosa, has decided to cause a fund for charitable and educational purposes only in relation to the disease and its effect on the community to be established.
- B. The Founder has paid to the Original Trustees the sum of \$100.00 to be held by them upon with and subject to the Trust's powers and provisions declared in this Trust Deed. Further money and also property and investments may from time to time be donated to the Trustee upon with and subject to the Trust's powers and provisions declared in this Trust Deed.

NOW THIS DEED WITNESSES as follows:

- I In the interpretation of this Trust Deed, the following words shall have the following meaning:

"the Trust Fund" means the sum of \$100.00 referred to in recital B and the accruing interest and the income thereof, the accumulations of income hereinafter directed to be made and also any additional moneys, investments or property which may from time to time be received by the Trustee to be held upon the trusts of this Trust Deed.

"this Trust Deed" means this deed including all amendments, additions, deletions or replacements lawfully made to this deed.

"the Trust" means the trusts established by this Trust Deed and it shall be known by the name set out in clause 2 hereof.

"Epidermolysis Bullosa" means a group of genetically determined disorders characterized by excessive susceptibility of the skin and mucosae to separate from the underlying tissues following mechanical trauma (or other related disorders so characterized as medical science may discover) and any illness or medical condition related to it or caused by it and means and includes the condition known as Epidermolysis Simplex, Dystrophic Epidermolysis Bullosa, and Junctional Epidermolysis Bullosa.

"the Act" means the Income Tax Assessment Act 1997 and includes regulations and other instruments under it and consolidations, amendments, re-enactments or replacements of any of them.

"Appointer" means the person holding the office of Appointer under clause 8.

"Approved Institution" means a fund, authority or institution which at the time of the provision of any money, property or benefit, falls within the description of an item in any of the tables in Subdivision 30-B of the Act, which has been established for charitable purposes.

"Director" means a director of the Trustee or any other company for the time being acting as trustee of the Trust Fund.

"Expenditure of the Trust" means expenditure incurred in relation to the operation of the Trust and includes direct fundraising expenditure and administration expenditure.

"Gift Fund" means the fund described in clause 9.

"Income of the Trust" means gifts, money received because of such gifts, government grants,

proceeds from fundraising, and proceeds from cause-related marketing campaigns and amounts from other sources that the Trustee deems appropriate.

"Trustee" means DEBRA AUSTRALIA Limited or any other trustee for the time being of the Trust.

- 2 The name of the Trust shall be "DEBRA AUSTRALIA".
- 3 The Trust is established and must be maintained exclusively for public charitable purposes which Trust fund must be used solely for the objects stated in 4 below, being:
 - (a) to an Approved Institution; and
 - (b) for any public charitable purpose set out in Subdivision 30-B of the Act.
- 4 Without limiting the generality of the objects described in clause 3, the specific objects of the Trust for which the Trust Fund must be applied solely for are for Approved Institutions, with preference being given to entities that:
 - (a) Promote the prevention and or the control of Epidermolysis Bullosa in all its forms;
 - (b) promote research into the cause, nature, and treatment of Epidermolysis Bullosa in all its forms;
 - (c) relieve physical and mental distress amongst persons suffering from Epidermolysis Bullosa by the provision of practical advice, guidance, and support and in such other ways as the Trustee determines.
 - (d) generally promote the health of groups of people who are suffering from Epidermolysis Bullosa;
 - (e) provide education about and promote personal lifestyles which relieve persons suffering from Epidermolysis Bullosa;
 - (f) assist people in households affected by Epidermolysis Bullosa by providing material, emotional and social support;
 - (g) encourage, assist, monitor and promote medical and scientific research into the causes prevention and cure of

Epidermolysis Bullosa;

- (g) promote and encourage self-help groups of people affected by Epidermolysis Bullosa;

The Trust may also solicit donations, gifts, bequests and other forms of assistance to or for the benefit of, the objects of the Trust, including by conducting fundraising activities.

5 Where a gift to an Approved Institution must be made for a specific purpose identified in the relevant provisions of Subdivision 30-B of the Act the Trustee may provide the money property or benefit to or for the Approved Institution only for the specified purpose.

6 The Trustee may apply capital as well as income of the Trust Fund for the purposes referred to in clause 3.

7

- (a) The Trust Fund shall be held and administered by the Trustee in accordance with the Trust.
- (b) The Trustee may retire on at least one month's written notice to the Appointer.
- (c) If the Trustee defaults in the observance or performance of any of its obligations or duties under this Trust Deed, the Appointer may by a written notice to the "Trustee remove the Trustee from office.
- (d) The Appointer must use its reasonable endeavours to ensure that if the Trustee retires or is removed, a successor Trustee agrees to become Trustee with effect from such retirement or removal becoming effective.
- (e) Any successor Trustee must execute a deed by which it covenants to be bound by this Trust Deed as if it had been originally party to it.
- (f) When it retires or is removed, the outgoing Trustee is released from all obligations in relation to the Trust Fund arising after the time it retires or is removed. The outgoing Trustee must execute and deliver any documents and do every other thing which is necessary or desirable to effect the appointment of the

successor Trustee.

- 8 (a) The initial Appointer is the Company Secretary of DEBRA AUSTRALIA Limited.
- (b) The Appointer may appoint a new Appointer by will, deed or notice in writing to the Trustee. If the Appointer dies without appointing a new Appointer, the legal personal representative of the Appointer is the new Appointer.
- (b) A person ceases to be the Appointer when they become a bankrupt, or make an assignment or composition with creditors.
- 9 (a) All other clauses of this Trust Deed are subject to this clause 9.
- (b) The Trustee must maintain, for the purpose of the Trust as noted in clause 3, a fund (Gift Fund):
- (i) to which gifts of money or property for that purpose are to be made; and
 - (ii) to which any money received because of such gifts is to be credited; and
 - (iii) that does not receive any other money or property; and
 - (iv) which complies with any other requirements specified in Subdivision 30-BA of the Act.
- (c) The Trustee must use the following only for the principal purpose of the Trust:
- (i) gifts made to the Gift Fund; and
 - (ii) any money received because of such gifts.
- (d) Notwithstanding any other provision in this Trust Deed, if the Gift Fund is wound up or if the endorsement (if any) under Division 30 of the Act of the Trust is revoked, any surplus assets of the Gift Fund remaining after payment of liabilities attributable to it, must be transferred to an Approved Institution.
- 10 (a) The Trustee must:
- (i) direct proper accounts to be kept by the person appointed by the Trustee for the purpose for all

sums of money received and spent by the Trust Fund, the matters for which the receipt and expenditure takes place and the assets and liabilities of the Trust Fund; and

- (ii) direct a statement of financial position, statement of financial performance and statement of cash flows be drawn up each year and make available to the person appointed by the Trustee for that purpose the documents and information that this person requires to fulfil their task.
- (iii) direct that money and property of the Gift Fund be separately identified in the accounts.

- (b) The accounts must be kept at the place which the Trustee determines and be open to inspection by any Director.
- (c) The Trustee may develop policies, procedures and guidelines to apply in determining which Approved Institutions the Trust will provide money, property or benefits to as prescribed in clause 3. The Trustee may publish such policies, procedures and guidelines.

11 In performing or exercising the trusts declared by this Trust Deed the Trustee has the following powers -

- (a) to receive and accept donations, gifts, bequests, legacies, grants and payments of money or any other property whatsoever PROVIDED only that where such donation, gift, bequest, legacy, grant or payment is made or given conditionally or subject to any trust, stipulation, request or expressed desire, the Trustee may only receive or accept it subject to the condition, trust, stipulation, request or desire (whether it has the force of law or not) if it is consistent with and encompassed by the specified purposes;
- (b) to invest and accumulate, subject to this Trust Deed, all moneys of the Trust Fund that are not paid away directly pursuant to the provisions of this Trust Deed in a common fund in their name or under their control or in the name of the Trust in any of the following investments, namely –
 - i. in any investment authorised by the laws of the Commonwealth of Australia or of a State or Territory of Australia, for the investment of Trust moneys;

- ii. in investment on deposit at interest with any trading or savings bank or with any permanent building society or any credit co-operative society; and
- iii. subject to paragraph 11(b)(i), in the acquisition by purchase, lease or otherwise of land or immovable property in any part of the world which may at the same time be used by the Trustees for the use or occupation or for any of the purposes of the Trust;

and the Trustee shall have power from time to time to sell or get in any investments or assets of the Trust Fund;

- (c) to open trading or savings bank accounts or permanent building society accounts or credit co-operative society deposit accounts for the general purposes of the Trust and for any special activity or purpose and deposit moneys of the Trust Fund in and to operate on such accounts and close such accounts from time to time;
- (d) to sell, exchange, lease, dispose of or otherwise deal with any property real or personal (other than money) for the time being subject to the Trust which in the opinion of the Trustee is not required (or in the case of a lease or other temporary disposition not immediately required) for the purposes of the Trust;
- (e) to borrow from time to time such sum or sums of money and on such term as the Trustee may think fit either on the security of all or any part or parts of the Trust Fund or otherwise and execute all necessary documents or deed in that behalf;
- (f) to compromise or compound all actions suits and other proceedings and all differences or disputes touching the Trust Fund or any part of it for the time being and refer any such differences or dispute to arbitration and adjust and settle all accounts and claims relating thereto;
- (g) to promote and carry into effect any fundraising activity of whatsoever nature and to receive donations, gifts or bequests of moneys, property or investments and to hold and stand possessed of the proceeds of the same as part of the Trust Fund;
- (h) to employ and pay any employee, agent or professional person to transact any business or do any acts

required or decided to be done in connection with the Trust including the receipt and payment of money and it is hereby declared that the Trustee shall not be responsible for the default of any such agent, employee or professional person or for any loss occasioned by his or her employment;

- (i) to act upon the opinion or advice of or information obtained from Barristers or Solicitors (whether instructed by the Trustee or by a third party) and act upon statements of information obtained from any bank, accountant, actuary, stockbroker or other person believed by the Trustee in good faith to be expert in relation to the matter upon which they are consulted and the Trustee shall not be liable for anything done or suffered by it in good faith in reliance upon such opinion, advice, statements or information and the Trustee shall be entitled out of the Trust Fund to be allowed and paid all charges and expenses incurred in obtaining such opinion or advice or information;
- (j) with the prior consent in writing of all the then Directors of Debra Australia Limited to modify, alter or extend by supplemental deed or deeds any of the Trust's powers or the provisions of this Trust Deed;
- (k) to pay first out of the Trust Fund all costs, charges and expenses incidental to the management of the Trust or to the exercise of any power, authority or discretion herein contained or the carrying out or performing of the Trust which the Trustee may at any time incur including all income tax (if any) or other taxes payable in respect of the Trust, costs in any way connected with the preparation and execution of these presents and all stamp duty, settlement duty, gift duty, probate duty, revenue duty or any other imposts or moneys of whatever nature payable in respect of these presents or the gifts or settlement hereby effected or in respect of any additional moneys or investments donated, paid or transferred to the Trustee upon the trusts hereof and whether under the laws of the Commonwealth of Australia or of any States or Territories thereof or any country;
- (l) to make, rescind and vary regulations (not being inconsistent with this Trust Deed) for the purposes of the administration of the Trust and the management of the Trust Fund and the conduct of their business;
- (m) to appoint such committees, as the Trustee shall think fit to assist it in the work of the Trust and may delegate to such committees such of its powers and duties as it thinks fit PROVIDED THAT the Trustee shall be informed of all acts and proceedings of any such committee as soon as practicable thereafter; and

- (n) to do all such other acts and things as shall from time to time be conducive or effective to attain the specified purposes or to give effect to the Trust.
- 12 Any Director being a solicitor or other professional person may be employed to transact any business or do any act required to be done in connection with the trusts hereof and shall be entitled to be paid all proper costs, charges and expenses for any professional business or act done by him or her or his or her firm in relation to the carrying out or performing of the Trust as he or she would have been entitled to receive in respect of such business if her or she had not been a Director.
- 13 Subject to the provisions of clauses 11(k) and 12, the Trustee cannot receive any remuneration from the Trust Fund but the Trustee and members of any committee established under sub-clause 11(m) may be reimbursed any proper out-of-pocket expenses actually incurred by them in carrying out their duties hereunder, including any expenses actually incurred by them in travelling to attend meetings of the Trustee or any committee appointed by the Trustee or actually incurred on behalf of the Trust subject to any regulations that the Trustee may make under sub-clause 11(1) as to the amount payable in respect of such expenses or the type of expense that may or may not be reimbursed.
- 14 (a) Except in the case of dishonesty or willful act or omission known to be a breach of trust, the Trustee shall be indemnified to the extent of the Trust held by it against all liabilities incurred by it in the execution or attempted execution or arising from or out of the execution or non-execution of the trusts authorities, powers and discretions of this Trust Deed.
- (b) References in this clause 14 to the Trustee include a Director and delegates appointed by it under this Trust Deed.
- 15 The receipt by the President, Treasurer, Chief Executive Officer or Secretary, by whatever name or title, of any Approved Institution to whom moneys are paid pursuant to this Trust Deed shall be sufficient discharge of the obligations of the Trustee hereunder and it shall not otherwise be responsible for the application of such moneys for any of the purposes specified herein.

- 16 The Trust may at any time be terminated at a meeting of the Trustee specially called for that purpose, subject to the prior approval of DEBRA AUSTRALIA Limited to such termination and provided that no less than six Directors are present at that meeting and vote in favour of the resolution for the termination of the Trust.
- 17 (a) If on the winding up or dissolution of the Trust Fund there remains after satisfaction of all its debts and liabilities any surplus assets, the surplus assets must be given or transferred to an Approved Institution which:
- (i) is maintained exclusively for or covenants to use the surplus assets exclusively for charitable purposes; and
 - (ii) prohibits the distribution of its income and property among its beneficiaries or members to an extent at least as great as is imposed on the Trust Fund.
- (b) The Approved Institution is to be determined by the Trustee at or before the time of dissolution or, failing such a determination, by a court of law.
- (c) An Approved Institution referred to in clause 17(a) includes any fund, authority or institution of which the Founder or a Director is the founder or a trustee or director or in respect of which the Founder or a Director is a director of its trustee.
- 18 This Trust Deed shall be governed by and construed in accordance with the laws of Queensland.
- 19 To ensure that the Trust Fund is controlled and administered by persons who because of their tenure of some public office or position or some activity in the community may be expected to have a high degree of responsibility to the public in exercising that control or administration, the following provisions apply:
- (c) the control of the Trustee is vested in the Directors who are appointed in accordance with the Schedule to this Trust Deed; and

- (d) subject to the Constitution of the Trustee, the number of Directors for the time being in office is not less than 5 but not more than 10.

SCHEDULE

Qualified Persons

- (a) All Directors must be a member of DEBRA AUSTRALIA Limited with at least three of the Directors being qualified as described in (b) below.
- (b) Qualified means a person who at the time of his or her first appointment as a director of the Trustee is a person who due to the tenure of some public office or position or activity in the community may be expected to have a high degree of responsibility to the public and including, but without limiting the generality of the foregoing, a person who is:
 - (i) a person who has a connection with Epidermolysis Bullosa including and not limited to a person with Epidermolysis Bullosa and or a carer, relative parent and or grandparent of such person;
 - (ii) a medical practitioner;
 - (iii) a former member of Debra Australia Inc and or National Dystrophic Epidermolysis Bullosa Research Association of Australia Incorporated.
 - (iv) a health professional including but not limited to nurses and persons in the pharmaceutical industry;
 - (v) a member of the Commonwealth or a State parliament;
 - (vi) a judge of a superior court in Australia;
 - (vii) a member of the council or governing body of an Australian university;
 - (viii) a professor at an Australian university;
 - (ix) a senior academic of an Australian University;
 - (x) a barrister or solicitor of the Supreme Court of an Australian State or Territory;

- (xi) a Fellow of the Royal Australasian College of Surgeons;
- (xii) a Fellow of the Royal Australasian College of Physicians;
- (xiii) a member of the Australian Society of Certified Practising Accountants;
- (xiv) a member of the Institute of Chartered Accountants in Australia;
- (xv) a Principal of an Australian school;
- (xii) a minister of a church;
- (xiii) a Justice of the Peace
- (xiv) a town clerk;
- (xv) a town councillor; or
- (xvi) a recipient of the Order of Australia or Governmental award for services to the public or community,
- (xvii) an academically qualified research scientist.

EXECUTED as a Deed on

22 January 2013

SIGNED, SEALED AND

DELIVERED by Francis Harper

Francis Harper
Signature

In the presence of:

[Signature]
Signature of Witness

STUART RICHARDSON
Print Name of Witness

Signed in accordance with the Constitution of DEBRA Australia Limited in the presence of:

[Signature]
Suzanne McKenna
Secretary

[Signature]
John Bacon
Director