



## Charity Trust Deed

## THIS DECLARATION OF TRUST IS MADE

the 1<sup>st</sup> day of March 2012 by

Christopher Peter Bedford-Gay: 1 Cumberland Road, Sale, Cheshire, M33 3FR

Rachel Elizabeth Jane Almeida: 66 White Horse Hill, Chislehurst, BR7 6DJ

Alison Catherine Louise Acosta Bedford: 26 Langdale Road, Sale, Cheshire, M33 4EN

(‘the first trustees’)

The first trustees hold the sum of

£ 100.

on the trusts declared in this deed and they expect that more money or assets will be acquired by them on the same trusts.

## NOW THIS DEED WITNESSES AS FOLLOWS:

### 1. ADMINISTRATION

The charitable trust created by this deed ('the charity') shall be administered by the trustees. (In this deed, the expression 'the trustees' refers to the individuals who are the trustees of the charity at any given time. It includes the first trustees and their successors. The word 'trustee' is used to refer to any one of the trustees.)

### 2. NAME

The charity shall be called: FOP Friends.

### 3. OBJECTS

The objects of the charity ('the objects') are:

The relief of distress and sickness for those affected by Fibrodysplasia Ossificans Progressiva (FOP) a tragic, degenerative and debilitating condition and to improve the lives of sufferers and their families.

To raise public awareness and understanding of Fibrodysplasia Ossificans Progressiva (FOP) and to promote education and research into the study and cure of FOP and related conditions.

To support charities and organisations undertaking charitable activities in both the UK and abroad who fund research, provide help, support, care and treatment for people affected by FOP and related conditions.

To support organisations researching treatments and a cure for FOP and related conditions.

The charity will carry out these objects by:

- Funding research related to the treatment and cure of FOP and related conditions.
- Funding organisations or charities in researching, providing help, support, care or treatment of FOP and related conditions.

### 4. APPLICATION OF INCOME AND CAPITAL

The trustees must apply the income and, at their discretion all or part of the capital, of the charity in furthering the objects.

### 5. POWERS

In addition to any other powers they have, the trustees may exercise any of the following powers in order to further the objects (but not for any other purpose):

(1) to raise funds. In exercising this power, the trustees must not undertake any taxable permanent trading activity and must comply with any relevant statutory regulations;

(2) to buy, take on lease or in exchange, hire or otherwise acquire property and to maintain and equip it for use;

(3) to sell, lease or otherwise dispose of all or any part of the property belonging to the charity. In exercising this power, the trustees must comply as appropriate with sections 36 and 37 of the Charities Act 1993, as amended by the Charities Act 2006;

(4) to borrow money and to charge the whole or any part of the property belonging to the charity as security for repayment of the money borrowed. The trustees must comply as appropriate with sections 38 and 39 of the Charities Act 1993, as amended by the Charities Act 2006, if they wish to mortgage land owned by the charity;

(5) to co-operate with other charities, voluntary bodies and statutory authorities and to exchange information and advice with them;

(6) to establish or support any charitable trusts, associations or institutions formed for any of the charitable purposes included in the objects;

(7) to acquire, merge with or enter into any partnership or joint venture arrangement with any other charity formed for any of the objects;

(8) to create such advisory committees as the trustees think fit;

(9) to employ and remunerate such staff as are necessary for carrying out the work of the charity;

(10) to do any other lawful thing that is necessary or desirable for the achievement of the objects.

## 6. STATUTORY POWERS

Nothing in this deed restricts or excludes the exercise by the trustees of the powers given by the Trustee Act 2000 as regards investment, the acquisition or disposal of land and the employment of agents, nominees and custodians.

## 7. DELEGATION

(1) In addition to their statutory powers, the trustees may delegate any of their powers or functions to a committee of two or more trustees. A committee must act in accordance with any directions given by the trustees. It must report its decisions and activities fully and promptly to the trustees. It must not incur expenditure on behalf of the charity except in accordance with a budget previously agreed by the trustees.

(2) The trustees must exercise their powers jointly at properly convened meetings except where they have:

(a) delegated the exercise of the powers (either under this provision or under any statutory provision),  
or

(b) made some other arrangements, by regulations under clause 22.

(3) The trustees must consider from time to time whether the powers or functions which they have delegated should continue to be delegated.

## 8. DUTY OF CARE AND EXTENT OF LIABILITY

(1) When exercising any power (whether given to them by this deed, or by statute, or by any rule of law) in administering or managing the charity, each of the trustees must use the level of care and skill that is reasonable in the circumstances, taking into account any special knowledge or experience that he or she has or claims to have ('the duty of care').

(2) No trustee, and no one exercising powers or responsibilities that have been delegated by the trustees, shall be liable for any act or failure to act unless, in acting or in failing to act, he or she has failed to discharge the duty of care.

## 9. APPOINTMENT OF TRUSTEES

(1) There must be at least three trustees. Apart from the first trustees, every trustee must be appointed for a term of 2 years by a resolution of the trustees passed at a special meeting called under clause 15 of this deed.

(2) In selecting individuals for appointment as trustees, the trustees must have regard to the skills, knowledge and experience needed for the effective administration of the charity.

(3) The trustees must keep a record of the name and address and the dates of appointment, re-appointment and retirement of each trustee.

(4) The trustees must make available to each new trustee, on his or her first appointment:

- (a) a copy of this deed and any amendments made to it;
- (b) a copy of the charity's latest report and statement of accounts.

## 10. ELIGIBILITY FOR TRUSTEESHIP

(1) No one shall be appointed as a trustee:

- (a) if he or she is under the age of 18 years; or
- (b) if he or she would at once be disqualified from office under the provisions of clause 11 of this deed.

(2) No one shall be entitled to act as a trustee whether on appointment or on any re-appointment as trustee until he or she has expressly acknowledged, in whatever way the trustees decide, his or her acceptance of the office of trustee of the charity.

## 11. TERMINATION OF TRUSTEESHIP

A trustee shall cease to hold office if he or she:

(1) is disqualified for acting as a trustee by virtue of section 72 of the Charities Act 1993 or any statutory re-enactment or modification of that provision;

(2) becomes incapable by reason of mental disorder, illness or injury of managing his or her own affairs;

(3) is absent without the permission of the trustees from all their meetings held within a period of six months and the trustees resolve that his or her office be vacated; or

(4) notifies to the trustees a wish to resign (but only if enough trustees will remain in office when the notice of resignation takes effect to form a quorum for meetings).

## 12. VACANCIES

If a vacancy occurs the trustees must note the fact in the minutes of their next meeting. Any eligible trustee may be re-appointed. If the number of trustees falls below the quorum in Clause 17(1), none of the powers or discretions conferred by this deed or by law on the trustees shall be exercisable by the remaining trustees except the power to appoint new trustees.

## 13. ORDINARY MEETINGS

The trustees must hold at least two ordinary meetings each year. Meetings may take any form, including videoconferencing and teleconferencing, as determined by the trustees.

## 14. CALLING MEETINGS

Ordinary meetings may be called at any time by the person elected to chair meetings of the trustees or by any two trustees.

Not less than ten days' clear notice must be given to the other trustees. The first meeting of the trustees must be called by Christopher Peter Bedford-Gay or, if no meeting has been called within three months after the date of this deed, by any two of the trustees.

## 15. SPECIAL MEETINGS

A special meeting may be called at any time by the person elected to chair meetings of the trustees or by any two trustees. Not less than four days' clear notice must be given to the other trustees of the matters to be discussed at the meeting. However, if those matters include the appointment of a trustee or a proposal to amend any of the trusts of this deed, not less than ten days' notice must be given. A special meeting may be called to take place immediately after or before an ordinary meeting.

## 16. CHAIRING OF MEETINGS

The trustees at their first ordinary meeting in each year must elect one of their number to chair their meetings. The person elected shall always be eligible for re-election. If that person is not present within ten minutes after the time appointed for holding a meeting, or if no one has been elected, or if the person elected has ceased to be a trustee, the trustees present must choose one of their number to chair the meeting.

The person elected to chair meetings of the trustees shall have no other additional functions or powers except those conferred by this deed or delegated to him or her by the trustees.

## 17. QUORUM

(1) Subject to the following provision of this clause, no business shall be conducted at a meeting of the trustees unless at least one-third of the total number of trustees at the time, or two trustees (whichever is the greater) are present throughout the meeting.

(2) The trustees may make regulations specifying different quorums for meetings dealing with different types of business.

## 18. VOTING

At meetings, decisions must be made by a majority of the trustees present and voting on the question. The person chairing the meeting shall have a casting vote whether or not he or she has voted previously on the same question but no Trustee in any other circumstances shall have more than one vote.

## 19. CONFLICTS OF INTERESTS AND CONFLICTS OF LOYALTIES

A charity trustee must:

(1) declare the nature and extent of any interest, direct or indirect, which he or she has in a proposed transaction or arrangement with the charity or in any transaction or arrangement entered into by the charity which has not been previously declared; and

(2) absent himself or herself from any discussions of the charity trustees in which it is possible that a conflict will arise between his or her duty to act solely in the interests of the charity and any personal interest (including but not limited to any personal financial interest).

Any charity trustee absenting himself or herself from any discussions in accordance with this clause must not vote or be counted as part of the quorum in any decision of the charity trustees on the matter.

## 20. SAVING PROVISIONS

(1) Subject to sub-clause (2) of this clause, all decisions of the charity trustees, or of a committee of the charity trustees, shall be valid notwithstanding the participation in any vote of a charity trustee:

(a) who is disqualified from holding office;

(b) who had previously retired or who had been obliged by this deed to vacate office;

(c) who was not entitled to vote on the matter, whether by reason of a conflict of interests or otherwise

if without the vote of that charity trustee and that charity trustee being counted in the quorum, the decision has been made by a majority of the charity trustees at a quorate meeting.

(2) Sub-clause (1) of this clause does not permit a charity trustee to keep any benefit that may be conferred upon him or her by a resolution of the charity trustees or of a committee of

charity trustees if, but for sub-clause (1), the resolution would have been void, or if the charity trustee has not complied with clause 19 (Conflicts of interests and conflicts of loyalties).

## 21. MINUTES

The trustees must keep minutes, in books kept for the purpose or by such other means as the trustees decide, of the proceedings at their meetings. In the minutes the trustees must record their decisions and, where appropriate, the reasons for those decisions. The trustees must approve the minutes in accordance with the procedures, laid down in regulations made under clause 22 of this deed.

## 22. GENERAL POWER TO MAKE REGULATIONS

(1) The trustees may from time to time make regulations for the management of the charity and for the conduct of their business, including

- (a) the calling of meetings;
- (b) methods of making decisions in order to deal with cases or urgency when a meeting is impractical;
- (c) the deposit of money at a bank;
- (d) the custody of documents; and
- (e) the keeping and authenticating of records. (If regulations made under this clause permit records of the charity to be kept in electronic form and requires a trustee to sign the record, the regulations must specify a method of recording the signature that enables it to be properly authenticated.)

(2) The trustees must not make regulations which are inconsistent with anything in this deed.

## 23. DISPUTES

If a dispute arises between the trustees about the validity or propriety of anything done by the charity trustees under this deed, and the dispute cannot be resolved by agreement, the trustees party to the dispute must first try in good faith to settle the dispute by mediation before resorting to litigation.

## 24. ACCOUNTS, ANNUAL REPORT AND ANNUAL RETURN

The trustees must comply with their obligations under the Charities Act 1993, as amended by the Charities Act 2006, with regard to:

- (1) the keeping of accounting records for the charity;
- (2) the preparation of annual statements of account for the charity;
- (3) the auditing or independent examination of the statements of account of the charity;
- (4) the transmission of the statements of account of the charity to the Commission;



- (5) the preparation of an Annual Report and its transmission to the Commission;
- (6) the preparation of an Annual Return and its transmission to the Commission.

## 25. REGISTERED PARTICULARS

The trustees must notify the Commission promptly of any changes to the charity's entry on the Central Register of Charities.

## 26. BANK ACCOUNT

Any bank or building society account in which any of the funds of the charity are deposited must be operated by the trustees and held in the name of the charity. Unless the regulations of the trustees make other provision, all cheques and orders for the payment of money from such an account shall be signed or witnessed by at least two trustees.

## 27. APPLICATION OF INCOME AND PROPERTY

(1) The income and property of the charity must be applied solely towards the promotion of the objects.

(a) A charity trustee is entitled to be reimbursed out of the property of the charity or may pay out of such property reasonable expenses properly incurred by him or her when acting on behalf of the charity.

(b) A charity trustee may benefit from trustee indemnity insurance cover purchased at the charity's expense in accordance with, and subject to the conditions in, section 73F of the Charities Act 1993.

(2) Subject to clause 28, none of the income or property of the charity may be paid or transferred directly or indirectly by way of dividend, bonus, or otherwise by way of profit to any charity trustee.

## 28. BENEFITS AND PAYMENTS TO CHARITY TRUSTEES AND CONNECTED

(1) General provisions

No charity trustee or connected person may:

(a) buy or receive any goods or services from the charity on terms preferential to those applicable to members of the public;

(b) sell goods, services or any interest in land to the charity;

(c) be employed by, or receive any remuneration from, the charity;

(d) receive any other financial benefit from the charity;

unless the payment or benefit is permitted by sub-clause (2) of this clause or authorised by the court or the Charity Commission ('the Commission'). In this clause a 'financial benefit' means a benefit, direct or indirect, which is either money or has a monetary value.

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## (2) Scope and powers permitting trustees' or connected persons' benefits

(a) A charity trustee or connected person may receive a benefit from the charity in the capacity of a beneficiary of the charity provided that a majority of the trustees do not benefit in this way.

(b) A charity trustee or connected person may enter into a contract for the supply of services, or of goods that are supplied in connection with the provision of services, to the charity where that is permitted in accordance with, and subject to, the conditions in, section 73A to 73C of the Charities Act 1993.

(c) Subject to sub-clause (3) of this clause a charity trustee or connected person may provide the charity with goods that are not supplied in connection with services provided to the charity by charity trustee or connected person.

(d) A charity trustee or connected person may receive interest on money lent to the charity at a reasonable and proper rate which must be 2% (or more) per annum below the base rate of a clearing bank to be selected by the charity trustees.

(e) A charity trustee or connected person may receive rent for premises let by the trustee or connected person to the charity. The amount of the rent and the other terms of the lease must be reasonable and proper. The charity trustee concerned must withdraw from any meeting at which such a proposal or the rent or other terms of the lease are under discussion.

(f) A charity trustee or connected person may take part in the normal trading and fundraising activities of the charity on the same terms as members of the public.

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## (3) Payment for the supply of goods only – controls

The charity and its charity trustees may only rely upon the authority provided by sub-clause (2)(c) of this clause if each of the following conditions is satisfied:

(a) The amount or maximum amount of the payment for the goods is set out in an agreement in writing between the charity and the charity trustee or connected person supplying the goods ('the supplier') under which the supplier is to supply the goods in question to or on behalf of the charity.

(b) The amount or maximum of the payment for the goods in question does not exceed what is reasonable in the circumstances for the supply of the goods in question.

(c) The other charity trustees are satisfied that it is in the best interests of the charity to contract with the supplier rather than someone who is not a charity trustee or connected person. In reaching that decision the charity trustees must balance the advantage of contracting with a charity trustee or connected person against the disadvantages of doing so.

(d) The supplier is absent from the part of the meeting at which there is discussion of the proposal to enter into a contract or arrangement with him or her or it with regard to the supply of goods to the charity.

(e) The supplier does not vote on any such matter and is not to be counted when calculating whether a quorum of trustees is present at the meeting.

(f) The reason for their decision is recorded by the charity trustees in the minute book.

(g) A majority of the charity trustees then in office are not in receipt of remuneration or payments authorised by clause 28.

(4) In sub-clauses (2)-(3) of this clause:

(a) 'charity' shall include any company in which the charity:

- (i) holds more than 50% of the shares; or
- (ii) controls more than 50% of the voting rights attached to the shares; or
- (iii) has the right to appoint one or more trustees to the board of the company.

(b) In sub-clauses (2) and (3) of this clause 'connected person' includes any person within the definition set out in clause 33 (Interpretation).

## 29. REPAIR AND INSURANCE

The trustees must keep in repair and insure to their full value against fire and other usual risks all the buildings of the charity (except those buildings that are required to be kept in repair and insured by a tenant). They must also insure suitably in respect of public liability and employer's liability.

## 30. EXPENSES

The trustees may use the charity's funds to meet any necessary and reasonable expenses which they incur in the course of carrying out their responsibilities as trustees of the charity.

## 31. AMENDMENT OF TRUST DEED

(1) The trustees may amend the provisions of this deed, provided that:

- (a) no amendment may be made to clause 3 (Objects), clause 8 (Duty of care and extent of liability), clause 27 (Application of income and property) and clause 28 (Benefits and payments to charity trustees and connected persons) , clause 32 (Dissolution) or this clause without the prior consent in writing of the Commission; and
- (b) no amendment may be made that would have the effect of making the charity cease to be a charity at law.
- (c) no amendment may be made to alter the objects if the change would undermine or work against the previous objects of the charity.

(2) Any amendment of this deed must be made by deed following a decision of the trustees made at a special meeting.

(3) The trustees must send to the Commission a copy of the deed effecting any amendment made under this clause within three months of it being made.

## 32. DISSOLUTION

(1) The trustees may dissolve the charity if they decide that it is necessary or desirable to do so. To be effective, a proposal to dissolve the charity must be passed at a special meeting by a two-thirds' majority of the trustees. Any assets of the charity that are left after the charity's debts have been paid ('the net assets') must be given:

(a) to another charity (or other charities) with objects that are the same or similar to the charity's own, for the general purposes of the recipient charity (or charities); or

(b) to any charity for use for particular purposes which fall within the charity's objects.

(2) The Commission must be notified promptly that the charity has been dissolved and, if the trustees were obliged to send the charity's accounts to the Commission for the accounting period which ended before its dissolution, they must send the Commission the charity's final accounts.

### 33. INTERPRETATION

(1) In this deed:

all references to particular legislation are to be understood as references to legislation in force at the date of this deed and also to any subsequent legislation that adds to, modifies or replaces that legislation

(2) 'connected person' means:

(a) a child, parent, grandchild, grandparent, brother or sister of the trustee;

(b) the spouse or civil partner of the trustee or of any person falling within paragraph (a) above;

(c) a person carrying on business in partnership with the trustee or with any person falling within paragraph (a) or (b) above;

(d) an institution which is controlled –

(i) by the trustee or any connected person falling within paragraph (a), (b), or (c) above; or

(ii) by two or more persons falling within sub-paragraph (d)(i), when taken together

(e) a body corporate in which –

(i) the charity trustee or any connected person falling within paragraphs (a) to (c) has a substantial interest; or

(ii) two or more persons falling within sub-paragraph (e)(i) who, when taken together, have a substantial interest.

(3) Paragraphs 2 to 4 of Schedule 5 to the Charities Act 1993 apply for the purposes of interpreting the terms used in sub-clause (2) above.



3. SIGNED AS A DEED BY: ALISON CATHERINE LOUISE ACOSTA BEDFORD

3(a) Signed:

on this            (day) of                            (month)                            (year)

3(b) in the presence of (print name):

Signed:

Address:

4. SIGNED AS A DEED BY: FIONA WHITE

1(a) Signed:

on this            (day) of                            (month)                            (year)

1(b) in the presence of (print name):

Signed:

Address:

5. SIGNED AS A DEED BY: JOHN LEVER

1(a) Signed:

on this            (day) of                            (month)                            (year)

1(b) in the presence of (print name):

Signed:

Address:



6. SIGNED AS A DEED BY: HELEN BEDFORD-GAY

1(a) Signed:

on this            (day) of                            (month)                            (year)

1(b) in the presence of (print name):

Signed:

Address:

7. SIGNED AS A DEED BY: NICKY WILLIAMS

1(a) Signed:

on this            (day) of                            (month)                            (year)

1(b) in the presence of (print name):

Signed:

Address: