



VHL UK/Ireland Charity Constitution 2016-05-14

1. Name

The name of the charity is VHL UK/Ireland.

2. Objectives

To relieve the charitable needs of persons who have von Hippel-Lindau Syndrome (VHL) and similar genetic conditions such as Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC) AND Birt-Hogg- Dubé Syndrome (BHD) and their families and carers in the UK and Ireland for the public benefit in particular but not exclusively by:

- 1) Providing support and advice regarding their genetic conditions,
- 2) Providing funds for research into the genetic conditions and for equipment to assist with such research,
- 3) To advance the education of the public in all matters concerning the genetic conditions.

3. Powers

The charity shall have the following powers, which may be exercised only in promoting the above objectives:

- To invite and receive funds;
- To work with other organisations at local, regional, national and international level;
- To promote the work of the charity and its activities;
- To hire or buy equipment or premises;
- To employ paid or unpaid staff, volunteers and advisers;

*This is a true copy
of original
signed [signature]
Chair 18/8/2016*

- To advance the wellbeing of people affected by VHL and similar genetic conditions like HLRCC and BHD, by ensuring they have a strong voice in all matters that affect their lives;
- To campaign, in furtherance of the objects and purposes of the charity, to improve the lives of people with VHL and similar genetic conditions like HLRCC and BHD, their families and carers;
- To do any other activity within the law that allows the charity to meet its aims and objectives.

4. Membership

4.1 Membership is open to everyone with an interest in the work of the charity.

4.2 The charity has the following categories of membership:

- Full membership

This includes voting rights (one per branch/organisation) and is open to voluntary sector and charitable organisations whose primary aim is to improve the quality of life for people affected by VHL and similar genetic conditions like HLRCC and BHD;

- Associate membership

With no voting rights, membership is open to organisations with some responsibility for the provision, commissioning or development of services for the welfare of people affected by VHL and similar genetic conditions like HLRCC and BHD;

- Full individual membership

This includes voting rights and is open to anyone diagnosed with VHL and similar genetic conditions like HLRCC and BHD, or directly affected by such a diagnosis, including families, friends and carers;

- Associate individual membership

With no voting rights, membership is open to anyone not directly affected but interested in a personal or professional capacity in VHL and similar genetic conditions like HLRCC and BHD and the support of people affected by them.

4.3 Members will pay a subscription fee, which will be decided by the management committee ("the committee").

5. General meetings

5.1 The charity shall each year hold a general meeting as its annual general meeting ("AGM") to discuss the activities and management of the charity.

5.2 Annual accounts will be presented at the AGM.

5.3 Voting by members at the AGM shall be open and decided by simple majority of those present and voting.

5.4 Extraordinary general meetings ("EGMs") can be called to discuss urgent matters. Five voting members need to request an EGM for it to take place.

5.5 Notice of general meetings, EGMs and the AGM will be given to members at least 21 days before the meeting is to be held.

5.6 Minutes will be taken at all meetings and be distributed to the membership after the meetings.

5.7 All meetings may be held as telephone conference calls.

6. Management committee

6.1 The committee is the body responsible for the management of the charity and shall meet as required but not less than twice a year.

They are the trustees of the charity.

6.2 The committee will consist of at least three and no more than 15 members. Two committee members or one third of the committee, whichever is the greater, are needed at meetings for them to be quorate.

6.3 The committee has the power to co-opt other members onto the committee during the course of the year.

6.4 The committee will be elected by members at the AGM every year. In their first meeting following the AGM the committee will appoint its own chair, treasurer and secretary. The treasurer and secretary can also be co-chairs.

6.5 A committee member can step down at any general meeting if they give at least 21 days' notice that they intend to leave.

6.6 Committee members can step down temporarily during periods of ill health or caring responsibility and come back automatically without re-election with the agreement of the chair.

6.7 If a committee member fails to attend three consecutive meetings without giving apologies, the charity will take this as their resignation.

7. Finances

7.1 The income and property shall be applied solely towards the promotion of the objectives of the charity as set forth in the constitution and no proportion of them shall be paid or transferred directly or indirectly by way of profits to members of the charity.

7.2 This provision shall not prevent the payment in good faith by the charity of out of pocket expenses reasonably and properly incurred on behalf of the charity if required by volunteers, employees, and members of the charity.

7.3 The charity will have a bank account in the name of VHL UK/Ireland. The account will have a minimum of two signatories, one of which will be required to authorise payments and sign cheques. These two people must not be related or living together.

7.4 Ireland Charities Regulatory Authority - Standard clauses for constitutions of organisations (other than companies) and trusts

Income and Property

The income and property of the body shall be applied solely towards the promotion of main object(s) as set forth in this Constitution. No portion of the body's income and property shall be paid or transferred directly or indirectly by way of dividend, bonus or otherwise howsoever by way of profit to members of the body. No charity trustee* shall be appointed to any office of

the body paid by salary or fees, or receive any remuneration or other benefit in money or money's worth from the body. However, nothing shall prevent any payment in good faith by the body of:

- a) reasonable and proper remuneration to any member or servant of the body (not being a charity trustee) for any services rendered to the trust/body;
- b) interest at a rate not exceeding 1% above the Euro Interbank Offered Rate (Euribor) per annum on money lent by charity trustees or other members of the body to the body;
- c) reasonable and proper rent for premises demised and let by any member of the body (including any charity trustee) to the trust/body;
- d) reasonable and proper out-of-pocket expenses incurred by any charity trustee in connection with their attendance to any matter affecting the body;
- e) fees, remuneration or other benefit in money or money's worth to any Company of which a charity trustee may be a member holding not more than one hundredth part of the issued capital of such Company;
- f) Nothing shall prevent any payment by the body to a person pursuant to an agreement entered into in compliance with section 89 of the Charities Act, 2009 (as for the time being amended, extended or replaced).

*charity trustee as defined by section 2(1) of the Charities Act, 2009

8. Dissolution

8.1 If the members resolve to dissolve the charity the committee will remain in office and be responsible for winding up the affairs of the charity in accordance with this clause.

8.2 The committee must collect in all the assets of the charity and must pay or make provision for all the liabilities of the charity.

8.3 The committee must apply any remaining property or money:

- a. Directly for the objects;

b. By transfer to any charity or charities for purposes the same as or similar to the charity;

c. In such other manner as the Charity Commissioners for England and Wales ("the Commission") may approve in writing in advance.

8.4 The members may pass a resolution before or at the same time as the resolution to dissolve the charity specifying the manner in which the committee are to apply the remaining property or assets of the charity and the committee must comply with the resolution if it is consistent with paragraphs (a) - (c) inclusive in sub-clause (3) above.

8.5 In no circumstances shall the net assets of the charity be paid to or distributed among the members of the charity (except to a member that is itself a charity).

8.6 The committee must notify the Commission promptly that the charity has been dissolved. If the committee members are obliged to send the charity's accounts to the Commission for the accounting period which ended before its dissolution, they must send to the Commission the charity's final accounts.

8.7 Ireland Charities Regulatory Authority – Required Clause

Winding-up

If upon the winding up or dissolution of the body there remains, after satisfaction of all debts and liabilities, any property whatsoever, it shall not be paid to or distributed among the members of the trust/body. Instead, such property shall be given or transferred to some other charitable institution or institutions having main objects similar to the main objects of the body. The institution or institutions to which the property is to be given or transferred shall prohibit the distribution of their income and property among their members to an extent at least as great as is imposed on the body under or by virtue of Clause 7.4 hereof. Members of the body shall select the relevant institution or institutions at or before the time of dissolution, and if and so far as effect cannot be given to such provisions, then the property shall be given or transferred to some charitable object with the agreement of the Charities Regulator. Final accounts will be prepared and submitted that will include a

section that identifies and values any assets transferred along with the details of the recipients and the terms of the transfer.

9 Amendments.

9.1 Clauses 1, 2, 7, 8 and 9 of this constitution may only be amended provided that:

- a. No amendment may be made that would have the effect of making the charity cease to be a charity at law;
- b. No amendment may be made to alter the objects if the change would not be within the reasonable contemplation of the members of or donors to the charity;
- c. No amendment may be made to clause 7 without the prior written consent of the Commission;
- d. Any resolution to amend any of the above-mentioned clauses in this constitution is passed by not less than two thirds of the members present and voting at a general meeting.

9.2 Any other clause in this constitution may be amended, provided that any such amendment is made by resolution passed by a simple majority of the members present and voting at a general meeting.

9.3 A copy of any resolution amending this constitution must be sent to the Commission within 21 days of it being passed.

9.4 Ireland Charities Regulatory Authority – Required Clause

Additions, alterations or amendments

The organisation must ensure that the Charities Regulator has a copy of its most recent governing instrument. If it is proposed to make an amendment to the governing instrument of the organisation which requires the prior approval of the Charities Regulator, advance notice in writing of the proposed changes must be given to the Charities Regulator for approval, and the amendment shall not take effect until such approval is received.

10. Adoption of the Constitution

This constitution was adopted by the members present at the meeting held on:

Date: August 4th, 2016

Committee member 1

Name: Graham Lovitt

Signature:

Committee member 2

Name: Nat Mason

Signature: