



Minutes of the Annual General Meeting

VHL UK/Ireland Committee - Thursday 12 May 2016, 7.30 p.m. by Skype Conference Call

Present: Graham Lovitt, Chair, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Nat Mason, Co-Chair, Treasurer, Trustee
Roxanne Bonin, Co-Chair, Secretary, Trustee, Marketing & Fundraising Officer
Tony Horton, Trustee, Scientific Advisor
Elaine Graham, Trustee
Gloria Proby, Trustee

- 1. Apologies** – were received from trustee Amy Henson and members Ellen Wentworth and Tasha Hearne.

2. Trustees

The following trustees were elected unanimously:

Graham Lovitt
Nat Mason
Roxanne Bonin
Janice Hepworth
Amy Henson
Elaine Graham
Gloria Proby
Tony Horton

Phil Tingle resigned during 2015/16.

John Pickering had notified the secretary that he no longer wishes to continue as a trustee.

It was agreed that the two trustee vacancies would be filled as soon as possible:

Ellen Wentworth
John Hepworth

- 3. Minutes of the Meeting held 7 May 2015** were agreed and signed.

4. Presentation of Accounts

The accounts were presented, showing a cash balance at the year-end of £39,599. Fundraising has surpassed all expectations and with the grant from the Co-operative Bank covering administrative and marketing expenses we are in an excellent position to make further donations. A fundraising target of £80,000 over the two-year period 2015-2017 has been set.

It is intended to open a new bank account Ireland so that funds can be separated. This will allow accurate reporting to the relevant Charity Commissions.

The accounts were approved unanimously and Nat was thanked for his work.

5. Chair's Annual Report

Note this was our first year as a registered charity in England and Wales

The highlights of another very successful busy year were as follows:

Fundraising:

- Targets of £20,000, £30,000 and finally £40,000 were broken. Now replaced with a 2 year target of £80,000 for year ending April 2017
- We started with VHL Awareness Month May with 2015 Claire Hobson and team climbing Ben Nevis, Scotland and raising over £10,000
- We ended with Dave O'Brien + 10 others raise over £7,600 in Wicklow Goal Break 10km
- In between there were lots of smaller fundraising events
- Vixstar Summer Ball raised over £6,000 which we shared with the Alzheimer's Society
- Awarded £1,000 by the Community Directplus Donation Scheme run by the charity's bank
- the eBay charity shop continued to be popular for pin badges, t-shirts etc. set-up by Roxanne Bonin

Donations and Key Outgoings

- Genetic Centres in UK and Ireland receive patient information packs
- £4,995 donation for a L20001 Luna FL Automated Fluorescence Cell Counter to the Department of Medical Genetics, Cambridge
- First Support Group Meeting held in Guy's Hospital, London
- We have been active in negotiating with Professor Eamonn Maher on our next donation for either more equipment or to help fund a specific piece of research. We have agreed to continue raising funds this coming year to maximise the donation impact.

Other Activities

- Progressing charity registration in Ireland. We submitted an application in July which has been reviewed favourably. We are waiting final approval of our constitution from the CRA's legal department.
- Progressing a new website design using WordPress which will make it easier to maintain and be easier to use from smart phones and tablets

6. Any Other Business – none

Signature:  _____

Dated: 21st November 2017

Graham Lovitt - Chair