



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 12 May 2016, 8.00 p.m. by Skype Conference Call

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

1. **Apologies** – were received from Amy Henson and Elaine Graham.

2. **Election of Officers and Trustees for the year 2016/17:**

Graham Lovitt, Chair, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Janice Hepworth, Secretary, Trustee
Nat Mason, Treasurer, Trustee
Tony Horton, Scientific Adviser, Trustee
Amy Henson – Trustee
Elaine Graham – Trustee
Gloria Proby - Trustee

3. **Minutes of the Last Meeting** – were agreed and signed.

4. **Matters Arising and Action Points not on the Agenda**

4.1 Membership Register – to be updated on an ongoing basis. **ACTION Janice.**

4.2 Website Blog – Tony agreed to write a blog this weekend. **ACTION Tony.**

4.3 Roxanne has emailed the fundraising plan out to everyone.

4.4 Future Support Meetings – a provisional date has been arranged for a meeting on 22 October 2016 in Manchester. Gloria is still looking into the possibility of a further meeting in Ireland in 2017. To be a recurring agenda item for future meetings.

4.5 The article that Roxanne was working on about her family has appeared in a magazine and it is hoped that a further article will be published on another family. In the

meantime, the blog is being updated with family stories, with hopefully a new one being published every two months or so.

- 4.6 Use of Skype – Janice reported that she had looked into the possibility of using GoToMeeting as an alternative to Skype, but there was a monthly fee involved of about £30 per licence so this is not viable.

5. Financial Report

- 5.1 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.
- 5.2 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.

6. Marketing and Shop Report

- 6.1 New Website – still underway, although the work is being done by a volunteer, so it is slow progress. It is now with the developers for coding and will hopefully be finished this month.
- 6.2 New @vhl-uk-ireland.org.uk email addresses – have been set up for those who requested them. Graham to re-set the passwords as they expire every 6 months.
ACTION -GRAHAM
- 6.3 Facebook – has been very active for VHL Awareness Month already and the “Twibbon” has been very popular with 280 people using this.
- 6.4 Shop sales are going well and a free pin badge is being sent with every order during VHL Awareness month.
- 6.5 Give as You Live have asked for a picture from us to use in publicity as we are eligible to receive their Bronze Certificate. It was agreed that we would let them have the one of the group taken at the support group meeting last November.

7. Research Donations –

- 7.1 Graham has 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.

8. **Publication and Distribution of VHL Handbooks** – these are now printed and ready for distribution. Roxanne is to let us have one each (or more if requested). Gloria will send Roxanne a list of hospitals in Ireland who may find this relevant.

9. **Patient Advocacy**

9.1 The VHL Alliance responded to the question about there being a standardisation of VHL treatment across the country by saying that guidance is given in the handbook.

9.2 It was agreed that the poll about genetic centres is to be pinned to the top of the Facebook page so that people can keep contributing to this.

10. **Any Other Business**

10.1 **Independent Examiner for the Accounts** – it was agreed that Janice Hepworth would try to find a volunteer who is suitably qualified to inspect the accounts and sign them off for the Charities Commission submissions. **ACTION – JANICE**

10.2 **Ireland Charities Regulatory Authority** – it was agreed to circulate and agree any required additions to the Charity's Constitution as provided by the Ireland Charities Regulatory Authority. Subject to trustee agreement and provided there was no conflict with current wording the changes would then be implemented.

11. **Date and Time of Next Meeting**

11.1 Thursday 4 August 2016 at 7.30 p.m. by Skype.

Signature:  _____

Dated: 4th August, 2016

Graham Lovitt - Chair