



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 2 August 2018, 7.30p.m. by Skype Conference Call

Present: Graham Lovitt, Chair, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Tony Horton, Trustee, Scientific Advisor
John Hepworth, Trustee
Amy Henson, Trustee, Social Media Co-ordinator

1. **Apologies** – were received from Nat Mason and Gloria Proby.

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

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

3.1 Gift Aid – this has now been claimed. Graham requested that any money paid into the bank which can be gift-aided is referenced as such; alternatively please drop him an email to provide details. This is important as well for money collected in boxes and buckets as this can be gift-aided.

3.2 Visibility of Shop Income - ongoing. Need up to date spreadsheet information from Nat. Consideration needs to be given as to the best way to show this and to ensure that it is kept up to date. **ACTION – John, Nat, Roxanne**

4. **Financial Report**

4.1 The current balance at the Co-operative Bank is £77K. There is also €2,174 in the Ulster Bank.

4.2 £40,000 of this money is now ring-fenced for the Cambridge project.

4.3 COIF Deposit Fund – it was agreed that we would go ahead with this account. Signatories to be Janice and Nat. Funds can be transferred in electronically from the Co-op Account. Funds withdrawn can only be transferred into the main bank account of the charity. **ACTION - Janice.**

5. Marketing, Support Groups, Fund-Raising and Shop Report

- 5.1 Orders have been placed to replenish stocks of pin badges, wrist bands, buckets and pots.
- 5.2 Alison and Georgia McDonagh are keen to help in any way they can. Alison has been asked to work on the genetic centres review update and Georgia will keep an eye on our Facebook page to pick up any posts and messages that may need a response so that we don't miss anything.
- 5.3 The web-designer who helped us out with the design of artwork for the Awareness Month was very appreciative of her gift.
- 5.4 Support Group November 17th 2018, Cambridge. The admin issues re the booking of the room should be resolved next week and we can then open up the booking system.
- 5.5 Sheffield Patient Support Day – an excellent day at Sheffield University. Both patients and researchers got a lot from meeting with each other; patients being reassured that research is actually happening; researchers speaking to patients for the first time and learning how VHL is affecting people in real-life!
- 5.6 Roxanne has been looking into the possibility of charity fundraising through Facebook, but they require a lot of information. She will have another look at this and let us know what is needed. **ACTION – Roxanne**
- 5.7 The Amazon Smile fundraising has been set up and the link sent to Roxanne and Amy so that we can advertise this. **ACTION – Roxanne and Amy**
- 5.8 Roxanne is considering arranging another Ball in 2019. She will be attending the one organised by a patient in Cambridge later this year.
- 5.9 Wigan Ukelele Club – John and Janice had an excellent day at St. Anne's. The club raised over £550 for the charity. Letters of thanks have been sent.

6. Research Donations


- 6.1 We do not appear to have received the first invoice for the Grant Award made to the Cambridge University project. Janice to check with Nat. **ACTION – Janice**

7. Any Other Business

- 7.1 Amy is attending a Brain Tumour Support Group through her work in September. She will bring any useful information to the next meeting.
- 7.2 Amy has asked that a certificate be sent to her company as they sponsored her for £200 when she completed a half-marathon. To be arranged.

8. Date and Time of Next Meeting

8.1 Thursday 1 November 2018 at 7.30 p.m. by Skype.

Signature:  _____

Date: 3rd November 2018

Graham J. Lovitt – Chair