



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 1 November 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
Nat Mason, Co-Chair, Treasurer, Trustee
Tony Horton, Trustee, Scientific Advisor
John Hepworth, Trustee
Amy Henson, Trustee, Social Media Co-ordinator

1. **Apologies** – were received from Gloria Proby and Ellen Wentworth

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

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

3.1 Cambridge Project Grant Award – this has been delayed and as yet we have not received the first invoice for payment.

4. **Financial Report**

4.1 The current balance at the Co-operative Bank is £78,322. There is also €2,174 in the Ulster Bank. (N.B. £40,000 of this money is now ring-fenced for the Cambridge project).

4.2 COIF Deposit Fund – Janice apologised that she hadn't had the chance to look into this further as yet. **ACTION - Janice.**

4.3 Visibility of Shop Income – Roxanne needs the ball-park figures for the split of income streams so that she can design some info-graphics for the website. It would be better if current figures could be used and kept up to date going forward. **ACTION - Nat**

4.4 John asked if the 2017/18 figures could be made available for the external inspection as soon as possible. **ACTION - Nat**

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

- 5.1 Social Media is proving very successful for the Charity at the moment – thanks to Amy for doing a fantastic job! £50 has been spent recently on boosting posts in relation to the Support Group Meeting coming up later this month. Shop sales are steady at the moment.
- 5.2 The Charity Ball in October, organised by a VHL patient and her partner, raised approximately £4,500 - £5,000, which is an amazing achievement. Roxanne took some merchandise to sell on the night and raised £200 including donations.
- 5.3 Support Group November 17th 2018, Cambridge. We currently have 25 patients booked to come to the event at Addenbrooke's Hospital, including some new faces who haven't been to a group meeting before. It was agreed that next year we would re-name the event so that it is not perceived as being purely a "Support" group".
- 5.4 The possibility of holding the next event in either Dublin or Wales was discussed. Tony is based in Cardiff at the moment with access to the University facilities until June 2019 and he will look into the feasibility of this. **ACTION - Tony**
- 5.5 Facebook and Amazon Smile fund raising - Roxanne has been looking into the possibility of charity fundraising through Facebook, but they require a lot of information. Janice will have a look at this further. Amy will advertise Amazon Smile as this is now live. **ACTION – Janice and Amy**
- 5.6 Amy will also advertise the Give as You Live gift-card shopping (pre-loaded gift cards). **ACTION – Amy**
- 5.7 It was agreed that Christmas cards should be sent to our regular donors as a thank you for their support during the year.

6. Research Donations

- 6.1 Graham and Eamonn Maher will discuss plans for future donations at the Support Group later this month.

7. Any Other Business

- 7.1 Graham asked if we could consider making a donation to the Irish Cancer Charity, with a request that the funds that we give are earmarked for VHL research? We need to check out our Irish constitution to confirm that we are able to do this.
- 7.2 Changes have been announced in the press this week about the effect that genetic testing has on life insurance and its availability to patients. There is a consumer guide on this topic on the Gov.uk website.

8. Date and Time of Next Meeting

8.1 Thursday 7 February 2019 at 7.30 p.m. by Skype.

Signature: 

Graham J. Lovitt – Chair

Date: February 7th, 2019