

Minutes of the Trustee Meeting

Thursday 15 August 2019, 7.30p.m. by Video Conference Call using Google Hangouts

Present: Graham Lovitt, Chair, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Nat Mason, Co-Chair, Treasurer, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Tony Horton, Trustee, Scientific Advisor
John Hepworth, Trustee
Phil Tingle – Website Manager
Nancy Molyneaux – Patient Liaison

1. **Apologies** – were received from Ellen Wentworth and Gloria Proby
2. **Welcome to our new members!** Many thanks to Phil and Nancy for joining us this evening, and also to Chloe Binding, who will be our Fundraising Co-ordinator. Your help with the running of the charity is much appreciated.
3. **Minutes of the Last Meeting** – were agreed and signed.
4. **Matters Arising and Action Points not on the Agenda**
 - 4.1 VHL Alliance Handbook Follow-ups – still in hand. Roxanne will get the information to our volunteer Alison so that she can chase for feedback from the genetic centres.
ACTION – Roxanne
 - 4.2 Cancer Genetics Group Meeting, Cambridge. Tony gave a report on the meeting, including feedback on preferred screening guidelines. A full report is being written up by Dr. Richard Sandford. The recommendations made at the meeting may well become accepted guidelines if approved. Once the report is published, we can put a link to it on the website and Tony will write a lay-person version. Graham commented that it would be useful to see what differences there are between these new recommendations and those provided by the VHL Alliance. Graham also commented that new HLRCC Guidelines have been adopted. **ACTION - Tony**
5. **Financial Report**
 - 5.1 The current balance at the Co-operative Bank is £68,606. There is also £5,305 in the PayPal account and €885 in the Ulster Bank. (N.B. £20,000 of this money is now ring-fenced for the Cambridge project, plus a further £40,000 for the 100,000 Genomes Project).

- 5.2 Tax Exemption (Ireland) – Nat has requested online access to the account. The password will be sent to Janice. **ACTION - Nat**
- 5.3 Co-op Saving Account – still to be actioned. There has been an error at the bank and for some reason Janice is not listed as a signatory, despite Graham holding emails from the bank to the contrary. Once the signatory situation is sorted, the savings account will be opened. **ACTION – Janice**
- 5.4 Charity Commission Financial Review – there isn't enough financial detail in our constitution for Charity Commission purposes. John has obtained a draft Financial Policy for amendment/adoption, but this will not be for publication. It will be kept by the Trustees in case it is required by the Charity Commission in the future. **ACTION – John**
- 5.5 Facebook Donations – Graham is trying to resolve an issue with Facebook/Paypal where we donations from Japan which were 10-times the amount that the donors intended. The donors have received a full refund, but there are issues around the costs to the charity in terms of exchange rates etc., when the problem has arisen through no fault of our own. Graham suggested that we do not accept foreign currency transactions in the future.

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

- 6.1 Welcome again to the new marketing team of Phil, Nancy and Chloe. Graham will add Nancy to the telephone messaging service so that she can access and respond to messages as they arrive. It was agreed that Phil would put social media conversations onto the website.
- 6.2 Support Group, Birmingham 16 November 2019. The registration page has been set up, further advertising will be done shortly. Eamonn Maher will be attending and will give a research update. Kathryn Chapman will be one of the speakers, talking about the course she is taking on mental health and well-being. The remainder of the agenda is to be finalised. Georgia McDonough is helping with the organisation.
- 6.3 VHL/Alzheimer's Charity Ball, 5 October 2019. 140 tickets have been sold. 12 VHL patients are attending so far. A patient has very kindly donated £1,000 so that raffle prizes can be purchased. Amy will send a thank-you card.
- 6.4 Shop sales – steady.

7. Research Donations

- 7.1 The second payment to the Cambridge Project of £20K is due – awaiting invoice from Cambridge. Janice is to chase for information to go on the website.
- 7.2 There is approximately £10,000 available for new donations.

8. Any Other Business

8.1 Fundraising Register – Graham had recently sent information about this register to Trustees, asking if we should be listed. It was agreed that there is no need at the present time, as our fundraisers have specific links to VHL/HLRCC/BHD so will have no need to search this kind of register to find us.

8.2 Dropbox Membership File – needs to be updated. Graham will share the file with the new members so that they can add their details. We then need to consider updating the Charity Commission information and the Co-operative Bank details. Nat will check the Charity Commission website to see what information is required so that we can ensure that all the relevant information is available on the membership list.

8.3 Google Ads – we have now registered for Google Ads. Rox has a contact who will complete the set up for us at no cost.

9. Date and Time of Next Meeting

9.1 Thursday 21 November 2019, 7.30 p.m..

Signature:  _____

Date: November 21, 2019

Graham J. Lovitt – Chair