



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 4 August 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
Gloria Proby, Co-Chair, Trustee
Amy Henson, Trustee
Ellen Wentworth, Trustee
John Hepworth, Trustee

1. **Apologies** – were received from Tony Horton and Elaine Graham.
2. **Minutes of the Last Meeting** – were agreed and signed.
3. **Matters Arising and Action Points not on the Agenda**
 - 3.1 Membership Register – to be updated on an ongoing basis. **ACTION Janice.**
 - 3.2 Website Blog – **ACTION Graham and Tony.**
 - 3.3 Independent Examiner for the Accounts – John thanked Nat for sending the accounts information through. He is putting the accounts into the required format for the Charities Commission and they will be independently examined by Mr. Arthur Wigglesworth FCA.
4. **Confirmation of new trustees** – Graham welcomed Ellen and John to the meeting and thanked them for agreeing to join the committee. He also thanked Gloria Proby for agreeing to become a Co-Chair. The website has been updated with this information.
5. **Changes to Banking Arrangements** –
 - 5.1 Co-operative Bank - attached to the minutes at Appendix 1 is the detail of two resolutions required to enable Janice to become a signatory on the Co-operative bank account. Agreed.
 - 5.2 Ulster Bank Ireland Limited be requested to act as the bankers of the Organisation. Agreed.

5.3 Graham John Lovitt and Nathaniel Luke Mason are authorised to complete and sign the Ulster Bank Your Banking Requirements form including applying for Bankline Internet Banking Service on behalf of the organisation. Agreed.

6. Financial Report

6.1 The current balance at the bank is £41,169.57; plus £161 in the Paypal account. Graham is also holding a cheque for €1,000 which will be paid into the Ulster Bank account as soon as all the signatures have been obtained.

6.2 We have a balance of £31,000 to raise to achieve the two-year target of £80,000

7. Marketing, New Website and Shop Report

7.1 New Website – we now have a list of minor things to review and revise so that the website can be launched.

7.2 Fundraising – Roxanne is pushing to get events up and running. A further discussion was held on fundraising later in the meeting.

8. Research Donations –

8.1 Graham has not had any further contact with Eamonn Maher. He is concerned about leaving the money in the account for too long as we may lose the momentum of the fundraisers. If nothing is heard from Eamonn by Christmas, Graham will look for other researchers. The other alternative is to fund a specific research project.

8.2 A discussion took place about the amount of support work we are doing as opposed to raising funds for research. Suggestions were made as to how we could use some of the money raised for support (as well as the support groups and handbooks already produced), such as an informal dinner where patients' meals are paid for by the charity or perhaps sending vouchers for pamper days. The main concern is that whatever we do, has to be within the terms of our constitution.

9. **Publication and Distribution of VHL Handbooks** – these have now been distributed to genetic centres. Copies are to be sent to Trustees.

10. Support Group:

10.1.1 Manchester - confirmed as 22 October 2016. Roxanne will advertise again on FaceBook this weekend to try to get people to sign up. It was agreed that we would arrange a dinner after the event so that people can continue chatting afterwards as it was felt that things were cut short in London last year. Dr. Emma Woodward has agreed to be one of our speakers at this event, we just have to firm up the arrangements with her. She worked with Eamonn in Birmingham at the VHL clinic.

10.1.2 Dublin 2017 – Gloria has made some enquiries and we can hold the meeting at the premises of the Irish Kidney Association. There is a choice of venues dependent upon numbers. Hopefully to be arranged sometime between February and April 2017.

11. Fundraising Events, Charity Boxes, Gift-Aid

- 11.1.1 The Vixstar Masquerade Ball will take place on 30 September 2017.
- 11.1.2 Great North Run
- 11.1.3 West Highland Walk
- 11.1.4 Brighton to London Cycle Ride
- 11.1.5 Ladies Mini-Marathon in Dublin
- 11.1.6 Amy is still working hard with the shop sales
- 11.1.7 Ellen is working hard with the collection pots and has £240 to pay in when she is next near to a Co-operative Bank. We can claim gift-aid on small donations made to the charity pots.

12. Any Other Business

- 12.1 **Grand Challenge** – Birmingham University. John asked for an update on the email received from Victoria Heath about the Grand Challenge. This is a research project into developing a vaccination strategy for cancer and the team are looking to involve VHL patients in the research. Graham is awaiting confirmation that she has the approval to go ahead.

13. Date and Time of Next Meeting

- 13.1 Thursday 17 November 2016 at 7.30 p.m. by Skype.

Signature:  _____

Dated: 20th November 2016

Graham J. Lovitt – Chair