



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 7 February 2019, 7.30p.m. by Skype Conference Call

Present: Graham Lovitt, Chair, 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 Roxanne Bonin 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 Irish Cancer Charity Donation – Gloria has asked if this donation could be given to the VHL Alliance. Agreed €1,000 to be donated from the Ulster Bank Account.

4. Financial Report

- 4.1 The Annual Accounts to 5 April 2018 have been submitted to the Charities Commission in the UK and to the Charities Regulator in Ireland. Nat thanked John and Janice for arranging the independent examination report. The accounts show a net income of £24,196 after the purchase of £898-worth of shop stock.
- 4.2 To keep in line with Charity Commission requirements, we need to do a review of financial controls before the end of the current financial year. It was agreed that John would look into this. Nat is to let John have the log-in details for the Charity Commission. **ACTION – Nat/John**
- 4.3 The current balance at the Co-operative Bank is £85,500. There is also £2,537 in the PayPal account and €2,159 in the Ulster Bank. (N.B. £40,000 of this money is now ring-fenced for the Cambridge project, plus a further £40,000 for the 100,000 Genomes Project – see item 6.2).
- 4.4 COIF Deposit Fund – it was agreed that this would be put to one side for the time being. Now that the Cambridge Project is underway the balance will be below the Financial Compensation Scheme limits.

4.5 Visibility of Shop Income – Nat is aware that this is outstanding. **ACTION - Nat**

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

5.1 We have received donations from Facebook for the first time. Unfortunately, there is no information as to who has raised this money for us, so we can't send out certificates or thank people on the Facebook page. Janice is to try to find out how much has been received so that Amy can put a general "thank you" on the Facebook page. Graham asked if this is an efficient route for fundraising and if we can claim gift-aid. Apparently, the fundraiser can opt to give gift-aid. **ACTION – Janice/Amy**

5.2 BTMyDonate is ending at the end of June 2019. Several alternatives have been considered and GoFundMe seems to be the most cost-effective option. It was agreed that we would replace the link on our website to GoFundMe.

5.3 Support Groups – Tony advised that it is not now feasible for him to arrange a meeting in Cardiff. Oxford was mentioned as a possibility.

6. Research Donations

6.1 There will be an up-front payment to the Cambridge Project of £20K to ensure that a payment is made in this financial year.

6.2 Professor Eamonn Maher's team are looking to extract information from the data provided by the 100,000 Genomes Project that has been running up until recently. The VHL Alliance is funding this work until the end of August 2019 and it was agreed that we should take over from 1 September 2019. Cost £40,000. We need to make sure nearer the time that the two avenues of funding don't overlap.

6.3 Graham is aware that the HLRCC Alliance may require help with purchasing some equipment. A meeting has been arranged in March to discuss this.

7. Any Other Business

7.1 It was agreed that we would again support an attendee at the Supporting Young Adults conference in Florence, Italy. We will advertise on social media to see if anyone is interested in going.

7.2 VHL Alliance Handbook – Graham asked if we had had the feedback from Genetic Centres of the content/use of the handbook. Janice agreed to check with Roxanne to see if any feedback had been requested/received. **ACTION – Janice**

7.3 Graham, Tony, John and Janice will be attending the Cancer Genetics Group meeting in Cambridge in March. This involves high-level NHS professionals discussing the preferred standard treatment for four different rare diseases; VHL, BHD, non-syndromic PPGL and HLRCC disease.

1. Date and Time of Next Meeting

1.1 The AGM will be held on Thursday 30 May 2019 at 7.00 p.m., followed immediately by the Trustee Meeting. Both meetings to be held by Skype.

Signature: 

Graham J. Lovitt – Chair

Date: May 30th, 2019