



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 17 November, 2016, 7.30 p.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
Gloria Proby, Co-Chair, Trustee
Amy Henson, Trustee
John Hepworth, Trustee
Amy Hargreaves

1. **Apologies** – were received from Tony Horton, Ellen Wentworth 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 Tony.**

4. **Financial Report**

4.1 The current balance at the bank is £46.6K; the cheque for €1,000 will be paid into the Ulster Bank account as soon as the set-up process is completed; Alison O'Brien also has a cheque to pay into this account.

4.2 Gloria asked how many signatories are required to sign cheques etc. on the Ulster account. It was agreed any 1 from 4 in line with our UK accounts.

4.3 We have raised £56,000 out of the two-year target of £80,000.

4.4 Up to date figures are shared with Trustees via Drop Box

4.5 Janice now has internet access to the Co-operative Bank Account.

4.6 Fundraising – it was agreed to contact Eamonn Maher in February 2017 to see if he has any requirements for donations from the funds raised. If not, an agenda item will be tabled to discuss viable alternatives. **ACTION – Graham and Janice**

5. **Marketing, New Website and Shop Report**

5.1 New Website – now up and running. It is clearer and easier to navigate than the old one. Roxanne is awaiting the invoice.

5.2 Christmas Cards – it was agreed that 500 packs would be ordered at £1.30 per pack. Sale price agreed as £3.50 per pack, plus postage. Thanks were given to Amy Henson who has designed the cards and to Amy Hargreaves who has offered to send them out to purchasers. Roxanne will get them on eBay as soon as possible. Amy Henson will also design some Get-Well cards for us to send out to patients from the charity as and when required.

5.3 Masquerade Ball – the contract has been signed and the event will take place on 30 September 2017 at the Holiday Inn, Peterborough. Tickets estimated at £45 per head, or £400 for a table of 10 people. Some discussion took place about the possibility of a raffle for patients only, with the prize being a weekend away. Further ideas needed please!

6. **Support Group:**

6.1 Manchester – an excellent day and a great success. There were some new faces there who didn't attend the London meeting last year and the feedback forms were all very positive. Thanks were given to all the organisers of the event and the speakers for giving their time.

6.2 Dublin 2017 – Another lady has been in touch with us wanting to arrange a support group in Ireland but seems to be finding our structure for the day a bit overwhelming. Gloria is to get in touch with her so that we can try to sort something together. Roxanne will pass the details to Gloria. **ACTION – Roxanne and Gloria**

6.3 Scotland 2017 – it was suggested that we should have the next UK meeting in Scotland, but there is some doubt as to whether we can arrange two meetings in one year. To be discussed further.

7. **Any Other Business**

7.1 **TV Programme “This Time Next Year”** – featured VHL patient Kathryn Mallery and her family, who have successfully had a healthy baby born through surrogacy. Kathryn is to write a blog for our website to provide more details of her VHL issues as the programme itself concentrated more on the issues of surrogacy.


7.2 Amy Henson would like a charity box sending to her for work please. **ACTION – Ellen**

7.3 More people are selecting VHL as their chosen charity on eBay so we are getting additional donations from sellers.

7.4 John and Janice reported that they had spoken on Skype with the VHL patient from France who got in touch with us recently. Janice has also made contact on Facebook with a lady from Scunthorpe who had been asking how she could get support.

8. Date and Time of Next Meeting

8.1 Thursday 9 February 2017 at 7.30 p.m. by Skype.

Signature:  _____

Dated: 17th February 2017

Graham J. Lovitt – Chair