



## Minutes of the Trustee Meeting

### VHL UK/Ireland Committee

Thursday 9 February 2017, 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  
Tony Horton, Trustee, Scientific Advisor  
Amy Henson, Trustee  
John Hepworth, Trustee

1. **Apologies** – were received from Nat Mason, Gloria Proby, 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. It was agreed that this would be put onto Dropbox. **ACTION Janice.**
  - 3.2 Website Blog – **ACTION Tony.**
4. **Financial Report**
  - 4.1 The current balance at the bank is £47K; and the cheque for €1,000 has now been paid into the Ulster Bank account.
  - 4.2 The target for fund raising on the website is being maintained by Graham.
  - 4.3 The accounts and annual return have been submitted to the Charity Commission. Thanks to John Hepworth and Arthur Wigglesworth for their help in this matter.
  - 4.4 Ulster Bank account – there is an issue with the paperwork for setting up online banking access with this account but this is in hand and will be sorted soon.
5. **Marketing, New Website and Shop Report**
  - 5.1 Stock has been taken of pin badges, t-shirts etc. and more supplies will be ordered soon with Awareness Month coming up in May.

- 5.2 We have had an enquiry for 200 wrist bands, which we haven't purchased before. Roxanne is looking into this.
- 5.3 VHL Awareness Month – May 2017. Roxanne is working on an increased social media presence for this event.
- 5.4 Blogs – Roxanne asked for anyone to submit a blog for the website. She will chase the promised blog from Katherine Mallery about her experience of VHL and surrogacy.
- 5.5 Masquerade Ball – 30 September 2017 at the Holiday Inn, Peterborough. Roxanne is hoping that more patients will attend this year's event to raise awareness.
- 5.6 Graham asked about the possibility of having an Ebay account in Ireland and keeping some stock over there. Roxanne and Graham will look into this. **ACTION – ROXANNE AND GRAHAM.**
- 5.7 Amy Henson is looking into some information we have received about the possibility of producing a calendar for 2018. **ACTION – AMY**
- 5.8 Get well cards - it was agreed that we would buy some cards, rather than designing our own at this stage.

## 6. **Research Donations:**

- 6.1 Graham is awaiting a reply from Eamonn Maher about the next donation. It is looking more likely that we will have to find alternative uses for the funding (e.g. sponsoring a doctoral research project). To be discussed at the next meeting.
- 6.2 There is a VHL Symposium for patients between the ages of 18-27 taking place in Berlin in June 2017. Although we were originally told that the organisers (VHL-Europa) would pay for travel and accommodation for up to 3 people from the UK, they have now said that this is incorrect and that we would have to pay these costs. It was agreed that we would fund up to £250 each for up to 3 individuals and advertise the event on social media. Participants would be asked to do a blog for the website on their return.
- 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. **Support Group Meetings**

- 7.1 **Dublin** – this is on hold for the time being.
- 7.2 Roxanne will put a poll on Facebook to help decide where the next meeting should be.

## 8. Fundraising Events

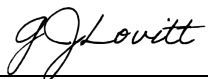
- 8.1 Fundraising is going fairly well at the moment. John is hoping (weather permitting!) to climb Ben Nevis in May and will get sponsorship.
- 8.2 We only have 3 charity buckets left.
- 8.3 The wedding is taking place next week of the couple who are hoping to raise awareness and funds by selling pins and having collection buckets.
- 8.4 Gift Aid – Graham will be applying for the Gift Aid to be paid to us next month, prior to our year end.

## 9. Any Other Business

- 9.1 Graham is hoping to move house soon and has asked if one of the other trustees will take on the responsibility of having the Charity's registered address at their home. To be decided – both John and Roxanne offered to do this.
- 9.2 Eurodis Membership – it was agreed that we would join this group at a cost of €75 to be paid from the Ulster bank account.

## 10. Date and Time of Next Meeting

- 10.1 The AGM will be held at 7 p.m. on Thursday 4 May 2017, immediately followed by the next Trustee Meeting at 7.30 p.m.

Signature: 

Dated: 21st November 2017

Graham J. Lovitt – Chair