



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 4 May 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
Nat Mason – Co-Chair, Treasurer, Trustee (Left the meeting at point 7)
Tony Horton, Trustee, Scientific Advisor
John Hepworth, Trustee
Amy Henson, Trustee (joined the meeting at point 7)

1. **Apologies** – were received from Amy Henson, Gloria Proby, Ellen Wentworth and Elaine Graham.

2. **Election of Officers and Trustees for the year 2017/18:**

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
Tony Horton, Scientific Adviser, Trustee
Amy Henson – Trustee
John Hepworth - Trustee
Elaine Graham – Trustee
Ellen Wentworth - Trustee

3. **Minutes of the Last Meeting** – were agreed and signed.

4. **Matters Arising and Action Points not on the Agenda**

4.1 Membership Register – to be updated on an ongoing basis. It was agreed that this would be put onto Dropbox. **ACTION Janice.**

4.2 EBay Account for Ireland – need to determine if there is enough interest in Ireland for an EBay account to be opened. **ACTION Graham and Roxanne.**

4.3 Calendar – to be held over to next meeting. **ACTION Amy.**

5. Financial Report

5.1 The current balance at the bank is £50K.

5.2 The Ulster Bank Account is now up and running. The €1,000 cheque has been paid in.

6. Marketing, New Website and Shop Report

6.1 Several new fund raising pages have been started in the last month.

6.2 Masquerade Ball – plans are going ahead for this event on 30 September 2017. Tickets are now on sale.

6.3 The shop has been re-stocked with pin badges. We need to order some more buckets. The wristbands are now on sale. A stock take is to be undertaken of all items.

6.4 VHL Awareness Month – May 2017. Roxanne and Amy are working hard on an increased social media presence for this event.

7. Research Donations:

7.1 Still no word from Eamonn Maher about using the funds we have available.

7.2 To support a PHD student, we would need £40-£50k over three years. It was asked if we could donate via research teams in the United States?

8. Support Group Meetings

8.1 The poll on FaceBook resulted in the favourite venue was Manchester, followed by Addenbrooks, Glasgow, Guys, Nottingham and Edinburgh.

8.2 It was felt that it would be better to have a new location, so Roxanne will contact Linzie Offord who lives in Scotland to get contacts from her hospital.

8.3 Dublin – there was a successful support group arranged in Dublin in April by a contact of Gloria's. There was some unfortunate misunderstanding about the support of the charity for this event and we need to learn from this. The charity is fully behind Ireland and will do anything we can to support patients in that country.

9. Fundraising Events

9.1 Fundraising is going fairly well at the moment.

9.2 There is to be a blog/FaceBook post to show the benefits of BT MyDonate as opposed to using Just Giving, which is more expensive in admin charges. We also need to

remind people using BT MyDonate that they can still use the paper sponsorship forms to donate. **ACTION Roxanne**

9.3 The old £5 notes are no longer legal tender. It was discussed that we should ask people to donate them to the charity as we can take them to the bank and pay them into our account. **ACTION Janice**

10. Any Other Business

10.1 Following the AGM, it is agreed that the charity address will be changed to 47 Tilm Lane, Retford, Nottinghamshire, DN22 6SN.

10.2 Janice and Roxanne are to be registered officials with HM Revenue and Customs. We will then have four officials – Graham, Nat, Roxanne and Janice.

10.3 VHL Europa – we need to decide our future stance on this event. We are supporting one delegate this year at a cost of €120 for airfare.

10.4 The Get Well soon cards have been purchased.

11. Date and Time of Next Meeting

11.1 To be arranged by email.

Signature:  _____

Date: 21st November 2017

Graham J. Lovitt – Chair