



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 31 August 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
Tony Horton, Trustee, Scientific Advisor
John Hepworth, Trustee
Amy Henson, Trustee

1. **Apologies** – were received from 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 – this has now been put onto Dropbox. Please can everyone check the file and update their records as necessary? **ACTION ALL.**
 - 3.2 EBay Account for Ireland – it was agreed that we would wait until we get more interest in Ireland before setting this up.
 - 3.3 2018 Calendars – it was agreed that we would not produce a calendar for sale as we cannot hold any unsold copies over to another year, as we can for the Christmas cards.
 - 3.4 We need to remind people that they can still use the paper sponsorship forms for donations and gift aid. John also explained to the meeting that the Gift Aid rules have changed slightly. If someone signs to say that we can claim gift aid on their donation, they must have paid enough tax to cover the gift aid amount. If not, the taxpayer may be held liable to re-pay the money to HMRC. Our forms (online and paper) need to be checked to ensure that we are notifying donors of this situation before they sign. John will help with this if needed. **ACTION – Roxanne**
 - 3.5 Old £5 notes – it was advertised that we will take any old-style £5 notes as a donation to the charity. There is a similar situation with £1 coins which go out of circulation on 13 October 2017. **ACTION - Janice**

4. Financial Report

- 4.1 The current balance at the Co-op Bank is £59,755.65.
- 4.2 The current balance at the Ulster Bank is €2,653.64
- 4.3 The issue of charges being incorrectly applied to the Ulster Bank account has now been resolved. The bank has made a €30 donation to the charity in consideration of admin time and inconvenience.
- 4.4 Graham reminded Nat to arrange charity status with the Revenue Commissioners in Ireland. **ACTION – Nat**
- 4.5 John asked Nat to provide the accounts to 5 April 2017 so that we can get them to the independent examiner in good time. Deadline for submission to the Charity Commission is 5 February 2017, but January is a busy time for accountants and it would be better if this is completed before Christmas if possible, especially as we are not charged for this work. **ACTION - Nat**

5. Marketing and Shop Report

- 5.1 Roxanne has added new merchandising stocks including a new design sports vest which will sell at £10 each.

6. Research Donations:

- 6.1 Eamonn Maher has been in touch to suggest that we help with paying the salary of a part-time research nurse who will be responsible for developing the IT programme previously discussed. There is a pilot scheme underway and a decision will be made as to whether or not the scheme is viable by the end of the year. If this goes ahead, we will be committed to a 2-year programme, costing £20K per year. This can be earmarked from existing funds. It was agreed that, should the scheme go ahead, this would be a good use of our funds for research. To be discussed further by the committee once the results of the pilot are known and more definite information is available.
- 6.2 Graham has also contacted Julie Adams, who works in Oxford and is on the HLRCC committee, to see if she has any requirements for funding.

7. Support Group Meetings

- 7.1 The Support Group meeting this year will be in Glasgow, on 4th November 2017, from 10 a.m. to 4 p.m. The format will be similar to last year.
- 7.2 There will be an advert on FaceBook for this event to encourage people to register and make a donation towards costs.

7.3 Speakers – we need ideas for speakers for the meeting and a poll for the most popular subject matters will go out on FaceBook. We need a speaker to talk about current research both here and in the USA. Tony will think about a suitable speaker.

ACTION – Tony

7.4 To save taking all of the merchandise all the way to Scotland, we will only take a sample of each item and then take orders on the day. These can be posted out later, but we will need to add an amount for postage and packing.

7.5 There has been a request for a child-friendly fun-day to be held. This would be an informal support group aimed at families with young children at a play centre of some kind. To be considered in 2018, maybe during the summer holidays.

8. Fundraising Events

8.1 Masquerade Ball – 230 tickets have been sold and table sponsorship is going well. We are doing our own table centre arrangements to keep the costs down. A goody-bag is to be provided to each of the 15 VHL patients that are attending. Collecting buckets, pots and merchandise will be available.

8.2 Fundraising events are going well, with several new BTMyDonate pages being set up recently.

8.3 Charity Boxes/Buckets – we can claim gift aid on these donations. The current boxes need to be checked and we need to try to get more out there. When we have new labels printed, we need to add the Ireland charity registration number. **ACTION – Roxanne.**

9. Any Other Business

9.1 Ring Central Telephone Messages – there have been a few voice-mail messages recently for which a notification goes to everyone on the admin@ email group. Janice raised concerns that we don't have a specific system for picking these messages up and responding to them. Roxanne picks up messages to do with fund raising. If anyone else responds to a message, please email the admin@ group to confirm that the call has been responded to.


9.2 VHL Europa – although this proved to be a worthwhile event for the young person that attended, it was confusing at the time as to exactly what costs we were expected to cover. The event will take place again in 2 years, so we need to be aware of the situation for next time so that an early decision can be made on our maximum donation.

9.3 There has been a request for some child-friendly Christmas cards to be designed and printed. Roxanne to look into this. **ACTION – Roxanne.**

9.4 Nat reported that he has recently changed his address. He will update the Charity Commission records (UK and Ireland), HMRC and the banks.

10. Date and Time of Next Meeting

10.1 23 November 2017, 7.30 p.m. by Skype Conference Call

Signature: 

Date: 3rd November 2018

Graham J. Lovitt – Chair