



## Minutes of the Trustee Meeting

### VHL UK/Ireland Committee

Thursday 6 August 2015, 7.30 p.m. by Skype Conference Call

**Present:** Graham Lovitt, Chair, Trustee  
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee  
Janice Hepworth, Secretary, Trustee  
Tony Horton, Scientific Adviser, Trustee  
Amy Henson, Trustee

1. **Apologies** – were received from Nat Mason, Gloria Proby, John Pickering and Elaine Graham.
2. **Minutes of the Last Meeting** – were agreed and signed. It was agreed that minutes of the Trustee Meetings would be published on the website, although some items may be omitted from the published version if deemed to be of a sensitive nature.
3. **Matters Arising and Action Points**
  - 3.1 Membership Register – has been created. Please notify Janice Hepworth of any updates to be made. Janice will go through the information she has re donations made and update the register. **ACTION JANICE HEPWORTH**
  - 3.2 Data Protection Act – we are not required to register for the purposes of the information we keep.
  - 3.3 Donations to Eamonn Maher – Graham has been in contact with Eamonn and the initial response was that we should purchase the cell counter at a cost of £4,995, which has been done. Eamonn has been asked for other suggestions for equipment but we should also consider funding other items e.g. specific research projects, travel to conferences etc. if they are relevant to the research being done. The caveat would be that we would need proof of the reasons for travel.
  - 3.4 Website Blog – Tony apologised that he hasn't done anything for the website as yet and will write something as soon as possible when he has spoken with Eamonn Maher. Graham said that he would provide Tony with the details of Eamonn's colleague who may be able to help. **ACTION TONY HORTON AND GRAHAM LOVITT**
4. **Trustee Resignation and Filling of Vacancy** – Phil Tingle has resigned from the Trustees. It was agreed that the post would not be filled at the moment.

5. **Financial Report** – in Nat’s absence, Graham gave a financial report to the meeting.

5.1 The total in Co-operative bank is £16,356.18 which includes £881.37 ring-fenced for admin and marketing purposes from the Co-op £1000 donation. There is also £415.32 in the PayPal account.

5.2 This is after paying for the cell counter. The funds raised by the Vixstar Ball have still to be received, as has a donation of £500 from Jacob’s Engineering.

5.3 We now have the facilities for people to donate by phone using JustText Giving; on-line donations and fundraising pages with BT mydonate, which is preferred now to EveryClick and Givey.

5.4 Graham has applied to Everclick for a package of web links to register for a Sainsbury’s shopping card which gives a 4% donation on all monies loaded onto the card.

6. **Marketing and Shop Report**

6.1 The Vixstar Ball was a huge success. As well as the funds raised by the ball, the sale of t-shirts, hoodies, badges and car stickers on the night raised £700. All of the stock was donated so the full £700 is available for charitable purposes.

6.2 Most of the contact cards have been given out – Roxanne will order some more ready for the support group event in November.

6.3 Five of the collecting “tins” have now been placed in businesses. Roxanne is to send one to John Hepworth for display in his office reception.

6.4 We now have an Instagram page available as well as the other social media sites, thanks to Amy for setting this up.

6.5 Handbooks – printing of the handbooks has now been approved by the VHL Alliance, although there is an update due in September so they won’t be printed until this has been done. They will be given to genetic centres and will be available for the support group event. Graham has received a donation of ten HRLCC handbooks from Joyce Graff.

7. **Donations (including £1,000 from Co-operative Bank for admin purposes)** – this item was discussed as part of matters arising.

8. **Setting of New Fund-Raising Target** – it was agreed that the new target would be £30,000.

9. **November 2015 Support Group – London**

- 9.1 Graham, Tony, Roxanne, Amy and Janice will all be attending the meeting. Hopefully the other Trustees will also be available.
- 9.2 The agenda for the day has not yet been finalised – Roxanne is in contact with St. Thomas and Guy’s Hospital. Specific speakers have still to be identified. The Cambridge research team are to be invited to speak and Tony said that he would be able to give a talk as well.
- 9.3 The event is to be advertised further on our website and on social media. It is hoped that some HLRCC/BHD patients will also be there.
- 9.4 BT mydonate has been set up to accept payment donations for the event.
- 9.5 Further meetings are to be arranged in Manchester and hopefully Northern and Southern Ireland.

#### **10. Any Other Business**

- 10.1 MacMillan Nurses have various premises that they own which we may be able to use for local group meetings. Graham has some contact with MacMillan and he will make enquiries. **ACTION GRAHAM LOVITT.**
- 10.2 Graham has submitted the application form to the Ireland Registration Authority and is awaiting a response.

#### **11. Date and Time of Next Meeting**

Thursday 19 November 2015 at 7.30 p.m.

Signature: 

Dated: 19 November 2015

Graham Lovitt - Chair