



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 11 February 2016, 8.00 p.m. by Skype Conference Call

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

1. **Apologies** – were received from John Pickering and Elaine Graham.
2. **Minutes of the Last Meeting** – were agreed and signed.
3. **Matters Arising and Action Points**
 - 3.1 Membership Register – to be updated on an ongoing basis. **ACTION Janice.**
 - 3.2 Website Blog – Tony agreed to write a blog for March, to be a “back to basics” summary of VHL as a lot of families struggle with this. **ACTION Tony.**
4. **Financial Report** –
 - 4.1 Nat is currently updating the accounts for presentation to the Charity Commission of Ireland and for the forthcoming AGM.
 - 4.2 Fund raising has been excellent this year. We have set a target of £40,000 and have donated £5,000 so far. There is currently £30,000 in the bank for donation purposes (less £500 being the balance of the Co-op fund for admin purposes).
 - 4.3 It was confirmed that any purchase of equipment for research purposes is VAT-free.
5. **Marketing and Shop Report**
 - 5.1 Roxanne has completed a plan for fundraising in the next 12-months and will email it out to everyone. She thanked Amy for her support and all the help she has given with boosting online fundraising. **ACTION - Roxanne**

5.2 Roxanne is looking to boost shop sales as stocks are quite high at the moment. VHL Awareness Month in May will hopefully kick-start this, together with the launch of the new website.

5.3 More volunteers are now on board to help with future support group meetings. Discussion was held about the possibility of meetings in London, Manchester and Ireland and Janice said that she would approach Sheffield to see if anything could be done there, perhaps in 2017. Perhaps the meetings could be less formal, without a strict programme of speakers to give families more time to discuss their own issues. There would still need to be at least one medical expert involved to answer any questions. **ACTION – Roxanne, Janice and Gloria**

5.4 Roxanne is in discussions with a magazine and hopes to get an article printed in May to highlight the situation of some VHL families. **ACTION - Roxanne**

6. **Research Donations –**

6.1 Graham is still in negotiations with Eamonn Maher and Carl Spickett of the Cambridge University Genetic Department to decide how best to spend the money raised. They are looking at a particular piece of equipment, but as yet we haven't got costs.

6.2 A discussion was held about the research report that has recently been on the internet about folded protein cells. The research at Cambridge is looking at VHL negative cells. Roxanne suggested that we could have a blog posting about the different types of research being carried out. **ACTION - Tony**

7. **Publication and Distribution of VHL Handbooks –** Roxanne is currently asking printers for prices to print the handbooks. Once printed, they will be posted out to genetic centres and given to support group participants. **ACTION - Roxanne**

8. **Patient Advocacy**

8.1 Nat asked about the possibility of providing advocacy services to patients who have been denied a particular treatment. The discussion evolved to the general topic of there being a standardisation of VHL treatment across the country, and whether or not there is a medical standard which should be adhered to? It was agreed that this should be something that the Charity can get involved in and that it would be looked into in more detail, possibly with the help of the VHL Alliance. Tony agreed to send an email to a contact of his and Graham agreed to contact the VHL Alliance. **ACTION – Tony and Graham**

8.2 Further to this, it was agreed that we should set up an online poll to ask people where they are treated and what kind of follow-up treatment they received; together with asking for an idea of how often they receive scans and what type of scans they receive. It seems to depend on the hospital as to whether people are getting regular MRI scans or CT scans. **ACTION - Roxanne**

9. Any Other Business

- 9.1 Ireland Charity Commission Registration – Graham has contacted the Commission to ask for an update on the position with our registration as it has now been six months since the application was submitted.
- 9.2 Graham commented that we can get Gift-Aid on the cash donated to the charity boxes after 6 April 2016. Roxanne stated that Ellen Wentworth is now managing the distribution of boxes and buckets.
- 9.3 The new domain server for the website gives us the ability to have @vhl.co.uk email addresses and mailboxes. Graham agreed to set these up for the Trustees as it gives more credence when we are emailing outside bodies. **ACTION – Graham**

10. Date and Time of Next Meeting

- 10.1 Thursday 12 May 2016 – AGM at 7.30 p.m. followed by committee meeting at 8.00 p.m.
- 10.2 Janice agreed to investigate the possibility of using “GoToMeeting” instead of Skype for future meetings. **ACTION – Janice**

Signature:  _____

Dated: 10-06-2016

Graham Lovitt - Chair