

Minutes of the Trustee Meeting

Thursday 21 November 2019, 7.30p.m. by Zoom Conference Call

Present: Graham Lovitt, Chair, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Tony Horton, Trustee, Scientific Advisor
Amy Henson, Trustee, Social Media Co-ordinator
John Hepworth, Trustee
Phil Tingle – Trustee, Website Manager
Nancy Molyneaux – Patient Liaison

1. **Apologies** – were received from Nat Mason, Ellen Wentworth and Gloria Proby
2. **Welcome to our new members!** Many thanks to Phil and Nancy for joining us this evening, and also to Chloe Binding, who will be our Fundraising Co-ordinator. Your help with the running of the charity is much appreciated.
3. **Minutes of the Last Meeting** – were agreed and signed.
4. **Matters Arising and Action Points not on the Agenda**
 - 4.1 VHL Alliance Handbook Follow-ups – still in hand. Roxanne will get the information to our volunteer Alison so that she can chase for feedback from the genetic centres.
ACTION – Roxanne
 - 4.2 Cancer Genetics Group Meeting, Cambridge. To carry over to next meeting. **ACTION - Tony**
5. **Financial Report**
 - 5.1 The current balance at the Co-operative Bank is £51,136. There is also £12,891 in the PayPal account and €870 in the Ulster Bank. The funding for the Cambridge Registry project has now been paid in full.
 - 5.2 Tax Exemption (Ireland) – The online password has now been received and this issue is in the process of being sorted. **ACTION - Nat**
 - 5.3 Co-op Savings Account – to carry over. **ACTION – Janice**
 - 5.4 Charity Commission Financial Review – John has now almost finished looking at the requirements and will send the information to Graham once complete. **ACTION – John**

- 5.5 Charities Aid Foundation (CAF) – a voucher has been received from the Boots Make a Difference Fund to the value of £436.55. Although we have an account set up with CAF, they require trustee details etc. to enable us to have online access. This is proving difficult with the changes to trustee details (Graham has updated the Charity Commission site). To save time and confusion, the voucher will be posted to CAF and the funds will be paid into our account.
- 5.6 Graham reported that a payment has been made of €65, being the renewal fee for the HLRCC website.

6. Marketing, Support Groups, Fund-Raising and Shop Report

- 6.1 The VHL/Alzheimer's Ball raised £6,500 net of expenses, split between the two charities. (There is also £500 to come back to the charity to refund expense costs). Fifteen patients attended – it was an excellent evening. Many thanks to Roxanne and her team for organising.
- 6.2 Merchandise/Shop – steady progress.
- 6.3 Social Media – Amy reported that postings are going well. Give as You Live reminders are to be posted for Black Friday and the Christmas Cards are to be advertised.
- 6.4 Awareness Month – May 2020. It was suggested that we should liaise with the VHL Alliance to produce a better campaign this year. Nancy has suggested that we take part in the “Pint of Science” project, which is a 3-day event in May. It involves talks in local pubs about specific topics. Nancy has a contact who knows Freek van Eaden (Sheffield University – he organised the research day for us in 2018) so hopefully he will be able to speak. Phil suggested that we should do another small video for the website, to include facts on awareness, research and wellness.
- 6.5 Website – the new website is now up and running, although there have been one or two glitches with being directed to other websites when clicking on our pages. Additional firewalls have been added so hopefully this will now be sorted. Phil will look further into the possibility of sending out regular newsletters to subscribers.
ACTION - Phil
- 6.6 Split of Roles – Roxanne is looking to take a step back from her fundraising role. Nancy is looking to take on this work.
- 6.6.1 Tony is happy to take on a “Research Liaison” role, so he will provide the information to Nancy/Amy for posting online. It was suggested that we get some information online about the Nobel Peace Prize and Nancy is thinking of doing an “annual review” of 2019 in December. Roxanne will set up a VHL Canva site for photographs to be used on the website.
- 6.6.2 Wellness Advocate – Kat Chapman (who undertook some wellness training on behalf of the charity and spoke at the recent Support Group about this) is going to provide snippets of information that we can publish over the next 12 months.

6.6.3 Roxanne has set up a Marketing Team Facebook group.

7. Patient Liaison and Support Group –

7.1 Patient Liaison - there have only been one or two messages on Facebook chat.

7.2 Support Group, Birmingham 16 November 2019. It was good to see some new faces at the Support Group meeting. The research update given by Professor Maher was very well received. We have had some good feedback from the day. Thanks again to Roxanne for organising. It was requested that someone else should take the lead on organising next year's event, please.

7.3 Graham has been asked to speak at a meeting for researchers and patients in Brussels in January 2020. Professor Eamon Maher will also be there.

8. Research Donations

8.1 Graham is to write to Cambridge to see if the 100,000 Genome Project is at a point where our funding can commence.

9. Any Other Business

9.1 It was suggested that a Donation Target should be put on the website at the start of the next financial year (April).

9.2 Life Insurance – patients with VHL struggle to get life insurance. Kat Chapman has asked if the charity would provide a letter of support for her to hopefully enable her to be able to buy life insurance. It was agreed that this could be done. There is some information on the Genetics Alliance website. Phil gave a summary of insurance offered by MetLife – he will send the details on to Kat.

9.3 DropBox – names and addresses to be updated please. **ACTION – Everyone**

9.4 Secretary role to be advertised on the website so that Janice can take over as treasurer from April.

10. Date and Time of Next Meeting

10.1 Thursday 27 February 2020, by Zoom online link.

Signature:  _____

Date: February 27th, 2020

Graham J. Lovitt – Chair