

Minutes of the Trustee Meeting

Thursday 11 June 2020, 7.30p.m. by GoToMeeting Conference Call

Present: Graham Lovitt, Chair, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Roxanne Bonin, Co-Chair, Marketing and Fund-Raising Officer, Trustee
Nat Mason, Co-Chair, Treasurer, Trustee
Amy Henson, Social Media Co-ordinator, Trustee
John Hepworth, Trustee
Francesca Goddard

1. **Apologies** – were received from Tony Horton, Ellen Wentworth, Gloria Proby, and Nancy Molyneaux.
2. **Welcome** – welcome to Francesca Goddard who is attending her first meeting. Thank you for joining us Frankie, your input and help with the charity is very much appreciated.
3. **Election of Officers for the 2020/21 year:**

Graham Lovitt, Chair, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Nat Mason, Co-Chair, Treasurer, Trustee
Amy Henson – Trustee, Social Media Co-ordinator
John Hepworth – Trustee
Gloria Proby – Co-Chair, Trustee
Kathryn Chapman – Patient Liaison, Trustee

The following members were not present at the meeting and are to be asked if they wish to continue in their roles:

Tony Horton, Scientific Adviser, Trustee
Ellen Wentworth – Trustee
Phil Tingle – Webmaster, Trustee

The role of Secretary is to be re-advertised so that Nat Mason can stand down as Treasurer (whilst continuing as a Trustee) and Janice Hepworth can move into the Treasurer role.

4. **Minutes of the Last Meeting** – were agreed and signed.
5. **Matters Arising and Action Points not on the Agenda**

5.1 VHL Alliance Handbook Follow-ups – to be carried over. **ACTION – Roxanne**

- 5.2 Cancer Genetics Group Meeting, Cambridge. To carry over to next meeting. **ACTION – Tony**
- 5.3 Dropbox name and address file – Graham to circulate again for updating. **ACTION – Graham**

6. Financial Report

- 6.1 The current balance at the Co-operative Bank is £34,549. There is also £15,257 in the PayPal account and €828 in the Ulster Bank. £10K of this money is ringfenced for the 100,000 Genome Project.
- 6.2 Tax Exemption (Ireland) – this is now approved; however, we still need to submit prior year tax returns. The income will be shown as zero taxable income. **ACTION – Nat**
- 6.3 Charity Commission Financial Review – John has produced a policy document which needs to be checked against the Charity's Constitution document and sent to Graham for approval - **ACTION – John**
- 6.4 Once all Trustees have confirmed (or otherwise) that they wish to continue in their roles, the bank mandate will be updated and HMRC will be notified of any changes.

7. Marketing, Support Groups, Fundraising and Shop Report

- 7.1 VHL Awareness Month – this went really well despite the COVID-19 lockdown being in force. We found new ways to engage with patients and their families, including an online coffee morning, a patient blog and a pub quiz. Thanks go to Amy and Frankie for organising these events. More online activity is to be organised in the future.
- 7.2 Fundraising – is quiet at the moment, but we are expecting approximately £1,000 from a virtual Victorian Bake-Off event organised by Debbie Clifton. Thank you, Debbie!
- 7.3 We are still hoping to develop an email database so that we can send messages to patients and families. It is only intended to send two per year, so they are not considered nuisance emails.
- 7.4 Merchandise/Shop – steady progress.

- 8. **Website** – Phil Tingle was not present at the meeting and we understand that he may be wanting to step down from his role as webmaster. Roxanne is getting used to the new functionality of the website, but it is less user-friendly than standard word-press and more technical than the old website. The website needs updating regularly to keep it fresh.

9. Patient Liaison and Support Group –

- 9.1 Patient Liaison – Frankie is taking on Nancy's role for the time being and will reply to any messages received.

9.2 Support Group 2020 – possibly to be held online. Ideas area needed, please. VHL Alliance have held online patient meetings lately, so they may be able to help us to set this up. Speakers could be arranged (perhaps Freek Van Eaden?); we could have a separate session on PGD and maybe a coaching taster session. A small donation could be asked for to show commitment – perhaps we could send a pin badge in return.

10. **Life Insurance Update – Kat** – some progress (pre-lockdown) has been made. A broker has found one insurance company who has agreed to take this further and asked for more information. The idea is that there will be a baseline cost for life insurance, then a points system would add a percentage to that fee for each VHL issue up to a maximum 200% weighting. As COVID-19 became an issue, 50% was added to everyone's baseline, so for now, Kat is unable to take out a policy. The Broker is asking for other people to apply to test the system – it was agreed that Kat would email the trustees of the charity to ask them to apply prior to the charity going public with this.
11. **Research Donations** - the 3rd payment for the 100,000 Genome Project was paid on 4 June. There is one more payment to be made for this project of £10,000.
12. **Any Other Business** – it has been discussed previously that we should have a fund-raising target on the website. It was felt that this issue should be left until after the COVID-19 pandemic has eased.

13. **Date and Time of Next Meeting**

13.1 Thursday 27 August 2020 by GoToMeeting conference call.

Signature:  _____

Date: August 27, 2020

Graham J. Lovitt – Chair