



Minutes of the Trustee Meeting

Thursday 30 May 2019, 7.30p.m. by Skype Conference Call

Present: Graham Lovitt, Chair, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Nat Mason, Co-Chair, Treasurer, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Tony Horton, Trustee, Scientific Advisor
John Hepworth, Trustee

1. **Apologies** – were received from Amy Henson, Ellen Wentworth and Gloria Proby

2. **Election of Officers for the 2019/20 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
Gloria Proby – Co-Chair, Trustee
Tony Horton, Scientific Adviser, Trustee
Amy Henson – Trustee, Social Media Co-ordinator
John Hepworth - Trustee
Elaine Graham – Trustee
Ellen Wentworth - Trustee

3. **Minutes of the Last Meeting** – were agreed and signed.

4. **Matters Arising and Action Points not on the Agenda**

4.1 Charity Commission Financial Review – John has the details from the Charity Commission website and will review our constitution to ensure that everything is up to date. **ACTION – John**

4.2 Shop visibility – no progress so far with this.

4.3 Facebook Donations – donations are arriving and can be gift-aided. The only issue is that we are not told who has raised the funds. Janice to check into this, Roxanne will advertise on the website that we are registered for this scheme. **ACTION – Roxanne/Janice**

- 4.4 VHL Alliance Handbook Follow-ups – Roxanne will get the information to our volunteer Alison so that she can chase for feedback from the genetic centres. **ACTION – Roxanne**

5. Financial Report

- 5.1 The current balance at the Co-operative Bank is £65,414. There is also £3,551 in the PayPal account and €899 in the Ulster Bank. (N.B. £20,000 of this money is now ring-fenced for the Cambridge project, plus a further £40,000 for the 100,000 Genomes Project).
- 5.2 Tax Exemption (Ireland) – we need to apply for an online account. Nat has asked for an application form to be sent out. Gloria and Graham are to be named as contacts as they both have an Ireland tax reference. **ACTION - Nat**
- 5.3 Co-op Saving Account – Janice reported that she has received an application form for a savings account with the Co-operative Bank. Interest rate 0.5%. Agreed that this would be opened. **ACTION - Janice**

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

- 6.1 VHL Awareness Month – has gone really well this year. People have been using the “Twibbon” and new artwork. Two patients, Kathryn and Georgia have been posting a “VHL Fact a Day” on Facebook. Other patients have been submitting photos for the website/social media pages. Roxanne will send thanks/goodies.
- 6.2 Georgia McDonough and her friend Tantara are attending the Florence Conference for young adults.
- 6.3 Support Group – no progress as yet. Birmingham was suggested as a possible venue.
- 6.4 Charity Ball – arrangements are in hand and are going well. Roxanne is looking for table sponsors and raffle prizes.
- 6.5 GoFundMe is our preferred option now that BTMydonate has ended. Roxanne will advertise this on Facebook.
- 6.6 Shop sales have gone well during Awareness Month.

7. Research Donations

- 7.1 There has been a payment to the Cambridge Project of £20K.
- 7.2 HLRCC - Graham and Tony visited the laboratory of Christian Frezza recently to discuss any possible help that we can provide.

8. Any Other Business

8.1 Supporting Young Adults conferences – it was agreed that we need early applications from possible attendees and that we would support a maximum of 2 delegates per year. It was also agreed that we would only support someone attending for a second time if no one else had applied in that year.

7.3 Cancer Genetics Group meeting, Cambridge, March 2019. We haven't received any feedback as yet from this meeting. Tony will chase. **ACTION – Tony.**

9. Date and Time of Next Meeting

9.1 Thursday 15 August 2019, 7.30 p.m..

Signature:  _____

Date: August 15th, 2019

Graham J. Lovitt – Chair