

Minutes of the Committee Meeting

Thursday 26 November 2020, 19:30pm by Conference Call

Present:

- Graham Lovitt, Chair, Trustee
- Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
- Janice Hepworth, Co-Chair, Treasurer, Trustee
- Tantara Fox-Stillwell, Secretary, Trustee
- Nancy Molyneaux, Patient Support
- Antony Horton, Trustee
- Amy Henson, Social Media Coordinator, Trustee
- Kat Chapman, Trustee
- Kim Vaughan, Trustee
- Nat Mason, Co-Chair, Trustee
- John Hepworth, Trustee

1. Apologies – Gloria Proby, Frankie Bryant, Ellen Wentworth, Trustee

2. Update on current trustees and their responsibilities

No new updates. ACTION – Tantara to remove from the agenda.

3. Minutes of last meeting

Minutes from the last meeting agreed.

4. Matters arising and action points not on the agenda

4.1 VHL Alliance Handbook

Kim and Roxy have met following the last meeting. Database has been provided to Kim to ensure information is up to date. Due to lockdown handbooks haven't been able to be handed over to Kim, looking to complete this in the first quarter of next year.

4.2 Cancer Genetics Group Meeting

Published report from Eamon Maher, this covers of much of where the funds have been used as part of the research. A copy of the report has been sent to Graham from Eamon with a confidentiality water mark. A message is going to be added to Facebook to make people aware of the report and to make contact if they wanted to be sighted. Graham has a confidentiality statement available to him which he will have a look at as a way to manage who has access to the report.

4.3 Dropbox name and address file to be updated

Dropbox has shown to be slightly unreliable when multiple people are updating to the spreadsheet. Agreed that if anyone's details change to contact Graham.

5. Financial report

5.1 Financial Report

PayPal	GBP 35,000
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Co-op UK	GBP 29,000
Ulster Ireland	Euro 1087
Paypal Ireland	Euro 0

5.2 Tax Exemption – Ireland

Ongoing. Completion of forms have taken place, should be sorted within the next week or two.

5.3 Co-op Bank Mandate

Still missing a few personal details forms. **ACTION** – those who haven't completed the form to complete as soon as possible.

We may look to change the bank from the Co-op to NatWest due to the online banking being difficult to use.

4.4 Charity Commission Financial Review

Completed. Janice emailed the policy to the group in the last 24 hours. Any queries to go back to John.

6. Marketing and fundraising and shop report

Coffee morning held on 15th November. 20 people in attendance. May wish to do a further one in the next few weeks.

Christmas cards being ordered. Amy Hargreaves will be taking over from Roxy on this and will be the point of contact.

Amy, Roxy and Frankie have been in discussion about a virtual 5k. People can fundraise and share on social media to help build awareness.

Spreadsheet has been created so we can track and ensure we send 'thank you' responses to people who have fundraised. This needs to be allocated to maintain our responses. **ACTION** – Roxy to speak to Frankie to see if she can support this piece of work.

Roxy has been contacted by Sharon re a support network for VHL patients in Scotland. Nancy has lead on this and there may not be enough coming her way if she was to do this separately however she could be a regional point of contact for any patients who make contact from Scotland.

7. Website

Website crashed back in August and hasn't changed much since. Graham has been in contact with someone in Ireland who has experience in building a website (quoted at Euro 500) and can get this completed before Christmas. Kat flagged that Shopify would be a better domain to use for the online shop if we were looking to grow the product line in the future.

8. Patient liaison and support group

Covered in marketing and fund-raising above. Sonia Law made contact with Nancy re her VHL story which the group agreed would be good to use for the new website.

9. Life insurance update

Roxy going to try to apply for life insurance and will feed back to the group. Nat is awaiting on his application, will update the group with the outcome.

10. Research donations

£20,000 donated by Charles White. £14,000 of this is going to Barts Hospital via Professor William Drake. Eamon Maher has been offered another £40,000 via a grant award. He will come back to us after the drafting of his report to see how this donation can be best utilised.

11. AOB

Nancy to draft an end of year summary. Nancy to create interactive courses and presentations which can be embedded into a website.

Group agreed that every three months a virtual coffee morning can be organised. Roxy to speak with Frankie to organise.

12. Date and time of next meeting

Thursday 25th February 2021 at 19:30pm

Signature: 

Graham J. Lovitt – Chair

Date: February 26th, 2021