

Minutes of the Committee Meeting

Thursday 27 August 2020, 19:30pm by Conference Call

Present:

- Graham Lovitt, Chair, Trustee
- Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
- Janice Hepworth, Co-Chair, Trustee
- Tantara Fox-Stillwell, Secretary, Trustee
- Nat Mason, Co-Chair, Treasurer, Trustee
- John Hepworth, Trustee
- Kim Vaughan, Trustee
- Amy Henson, Social Media Co-Ordinator, Trustee
- Ellen Wentworth, Trustee

1. **Apologies** – Apologies received from Kathryn Chapman, Gloria Proby.

2. **Update on current trustees and their responsibilities**

Added a biography page onto the website to list the roles and responsibilities. **ACTION** – those who want to roles and responsibilities to be added this to website to contact Graham.

3. **Minutes of last meeting**

Minutes from the previous meeting agreed. **ACTION** – Tantara to change the name of the meeting from ‘Trustee Meeting’ to ‘Committee Meeting’.

4. **Matters arising and action points not on the agenda**

4.1 VHL Alliance Handbook

This has been passed over to Kim. Roxy and Kim to have a handover meeting in the next week to look at what needs to be done. There may be a new handbook from the VHL Alliance – Joshua Mann is the point of contact for the handbook. We still have a number of older versions however the screening guidelines have been updated and therefore the handbook will need to be updated.

4.2 Cancer Genetics Group Meeting

Carry over to next meeting in Tony’s absence.

4.3 Dropbox name and address file to be updated

This guidance was changed after the meeting: Reminder for all to keep their details held on Excel spreadsheet on Dropbox up to date. **Please don’t edit directly** but send updates to gjlovitt@vhl-uk-ireland.org. We have had issues with people updating the Excel spreadsheet and losing the data.

5. Financial report

5.1 Financial Report

Graham to change the PayPal email over to a generic 'admin@VHL-UK-Ireland' to allow others to access the system.

PayPal	GBP 16,968.29
Co-op UK	GBP 36,235
Ulster Ireland	Euro 1102
Paypal Ireland	Euro 0

ACTION – Roxy to send Janice the account details for Birmingham Support Group catering costs.

5.2 Tax Exemption – Ireland

We do have Tax Exemption however still have the returns to submit for previous financial years.

5.3 Co-op Bank Mandate

ACTION – Janice to send out forms to all trustees to fill in address details and send back to the bank.

5.4 Charity commission financial review

Completed. John went through the constitution and the policy to ensure they are coordinated.

ACTION – Janice to send out to all trustees for approval at the next meeting. Tantara to add to the agenda for the next meeting.

6. Marketing and fundraising and shop report

Due to Covid we may still see an impact on fundraising. We may need to look at alternative campaigns in relation to fundraising. Shop is ongoing and will progress over the next few months.

7. Website

The website has had a few issues and the original error went away however a critical error appeared. The website allowed people to submit their stories via the website which created spam messaging. Graham re-added the plug-ins which were essential (such as PayPal functions) which has resolved the issue. Agreed it would be useful to recruit a website manager to have oversight of the website and changes that need to be made.

ACTION – Roxy to advertise for the website manager role via social media.

8. Patient liaison and support group

Scoping 14th/15th November 2020 for the next support group, which will be a virtual meeting. Look to arrange guest speakers and breakout sessions.

ACTION – Graham to link in with Prof Maher to see if he could attend to provide an update on research and possible Q&A. Roxy to contact Ilene Sussman to see if she would be willing to attend

and link in with Kat around wellbeing. Janice to contact Freek van Eeden at Sheffield University for an update on the zebra fish project.

9. Life insurance update

Janice reported that Kat had asked if any of the trustees had been successful in obtaining life insurance through the broker she is working with. No one had received Kat's email with the details, so Janice is to ask Kat to re-send to everyone. ACTION Janice

10. Research donations

Over £40,000 available. Group agreed to link in with Prof Maher to discuss future research projects.

ACTION - Graham to make contact to discuss future research projects with Prof Maher.

11. AOB

12. Date and time of next meeting

Thursday 26th November 2020 @ 19:30

Signature: _____



Graham J. Lovitt – Chair

Date: November 26, 2020