

Minutes of the VHL UK/Ireland Committee

Thursday 24 February 2022, 7.30 p.m. (online by Zoom)

1. Apologies

Nat Mason, Francesca Goddard, Gloria Proby, Nancy Molyneaux, Tantara Fox

Attendees

Graham Lovitt, Kathryn Chapman, Janice Hepworth, John Hepworth, Roxanne Bonin, Kim Vaughan, Amy Henson, Tony Horton.

2. Minutes of the last meeting were agreed.

3. Matters Arising and Action Points not on the Agenda:

3.1 VHL Alliance Handbook – Roxanne (now Kim).

Kim has 12 copies of the new handbook, which will be sent out if requested. The digital link to the website so it can be downloaded. (This item to now be removed from future agenda).

4. Financial Report – Janice

4.1 Financial Report

VHL Bank

Balances

		24/02/2022	25/11/2021	16/09/2021
Co-op	Sterling	47,101.02	45,790.37	43,573.89
Paypal	Sterling	829.08	159.57	20.92
Ireland	Euro	93.73	107.98	107.98

4.2 Ireland Bank Account – a decision is needed re the Ulster Bank account. The branch is closing later this year. Funds are dwindling due to bank charges (£14.25 per quarter) and the lack of fundraising in Ireland. The possibility was discussed of closing the Ireland account and transferring funds to the UK account. Janice will contact the Charities Regulator to see if we are able to continue as a registered charity in Ireland if we do not have a bank account in the country. **ACTION – Janice**

4.3 Charity Commission annual returns – have been completed in both UK and Ireland. Janice thanked Nat for his help with this process. The Ireland tax returns need to be brought up to date. **ACTION - Janice**

5. Marketing, Fund-Raising and Shop Report – Roxanne and Amy

5.1 Roxanne has replied to a query re the Great North Run. There has also been a query re the Three Peaks Challenge and the fundraising process for this.

5.2 Awareness Month May – Roxanne to contact the VHL Alliance and has asked for any ideas and suggestions to promote awareness. **ACTION - Roxanne**

5.3 It is hoped that Vixstar will organise a ball in 2023. Frankie and Dean have decided to cancel their proposed ball in 2022.

5.4 Social Media – it is hoped that momentum will pick up again now that Kayleigh Stevens is recovering and will be able to give some time on this.

5.5 Shop stocks are low, although we are only getting one or two orders per month at the moment.

6. Website – Graham. The website is running smoothly. Roxanne asked if it is linked to Google Analytics, Graham to check. **ACTION - Graham**

7. Patient Liaison and Support Group – Roxanne

7.1 Roxanne is making enquiries with London hospitals to see if it is feasible for us to have a support group meeting in November 2022. It will of course depend on COVID regulations.

7.2 Ring Central – not many calls are coming through, most people tend to message the charity if they need anything. It was agreed that this would be discontinued, which would be a saving of £17.99 per month; and that the contact details on the website would be checked/updated. **ACTION - Graham**

8. Life Insurance Update – Kat
No further updates.

9. Research Donations – Graham

9.1 Research funding – Crick Institute, Professor Drake. Nothing has been heard since 19 January 2022. Janice to email again. **ACTION – Janice**

9.2 Graham reported that the BHD Foundation has a new CEO who is progressing their fundraising initiatives. It was suggested that the three groups (VHL/HLRCC/BHD) should make better use of the synergy within the groups. We should be comparing notes on research projects and maybe look towards some joint funding. Graham has updated our website to show how the three groups join together.

10. NICE Appraisal Sub-Group & Support Team Sub-Group – Kat

10.1 We are currently awaiting an update meeting with Merck.

10.2 Kat should have some time this week to get the survey data ready for the website.

10.3 NICE has emailed to say that the 8-week call should come in July 2022.

11. Any Other Business

11.1 Rare Disease Day 28 February 2022 – Roxanne to post some information on social media. **ACTION – Roxanne**

12. Date and Time of Next Meeting

Thursday 26 May 2022 – AGM at 7 p.m., followed by Committee Meeting at 7:30pm

ACTION – All – please indicate to Tantara if you are happy to continue in your current role within the charity.

Signature: 

Dated: May 26th, 2022

Graham Lovitt - Chair