



Minutes

VHL UK/Ireland Committee

Thursday 25th November 2021, 7.30 p.m.

1. Apologies

Ellen Wentworth, Frankie Bryant, Nancy B

Attendees

Kim Vaughan, John and Janice, Roxanne Bonin, Amy Henson, Kat Chapman, Nat Mason, Tony Horton. Graham Lovitt.

2. Minutes of the last meeting

Minutes agreed by group

3. Matters Arising and Action Points not on the Agenda

3.1 VHL Alliance Handbook – Roxanne (now Kim)

Kim now has the handbooks. Roxanne has added the digital link to the website so it can be downloaded. Kim has 12 hard copies of the handbook if a physical copy is requested.

RCCL Family Alliance have been provided permission to take information from the VHL handbook for their literature.

4. Financial Report – Graham/Nat/Janice

4.1 Financial Report

VHL Bank Balances

		<u>25/11/2021</u>	<u>Sep-21</u>
Co-op	Sterling	45,790.37	43,573.89
Paypal	Sterling	159.57	20.92
Ireland	Euro	107.98	107.98

NB Cheque for £1,189 still to be credited to Co-op bank

PayPal donation of £100 has been received. The group agrees to regular posts on social media channels to thank the public for their donations.

Janice has looked at options for the NatWest account however the registration is time consuming. Group agreed to remain with the coop.

The accounts for April 2021 are with the independent examiner, they should be back in the next week and be sent to the charity commissioner.

4.2 Tax Exemption – Ireland

We have needed to reapply due to expiration of the digital certificate. This has been re-requested and can then be further progressed.

5. Marketing, Fund-Raising and Shop Report – Roxanne, Amy and Chloe
Looking to schedule a number of comms over the next month, including charity Christmas cards.

We are receiving posts across social media asking similar questions so looking to regularly share comms on frequent Q&As.

Roxanne proposed that a coffee morning could be arranged into the New Year and that we could assess the situation around face to face events into 2022.

6. Website – Graham
No further updates.
7. Patient Liaison and Support Group - Nancy
No further updates.
8. Life Insurance Update – Kat
No further updates. Kat has enquired however communication has been slow, this is being progressed however we may need to look at other insurers.

Nat has also been looking at life insurance and Legal & General were able to provide insurance in principal.

9. Research Donations – Graham
Graham updated that we are currently building funds and looking into potential research work for the new year.
10. BHD and HLRCC
Reminder that as a charity we also support these conditions. We don't have a representative on the committee for BHD, group agreed to look at inviting someone along. ACTION – Graham to make contact to invite a representative.
11. NICE Appraisal Sub-Group & Support Team Sub-Group – Kat
Bulzutfan approval seems to be slowing down. Kat is in regular contact with NICE and other relevant organisations. We are awaiting a request from NICE which we are prepared for.

An email has been received from Prof Maher re clinical trials however no information was given on what treatment was to be trialled.

Action – Kat to compose some comms to go out on social media re Belzutifan progress.

12. Any Other Business
No AOB

13. Date and Time of Next Meeting
Thursday 24th Feb 2022 – 7:30pm

A handwritten signature in black ink, appearing to read 'G. Lovitt', written in a cursive style.

Signature:
Graham J. Lovitt – Chair

Date: February 24th, 2022