



Minutes

VHL UK/Ireland Committee

Thursday 26th May 2022, 7.30 p.m.

1. Apologies - Francesca Goddard, Ellen Wentworth and Gloria Proby.
2. Minutes of the last meeting
Minutes agreed.
3. Re-appointment of trustees

The following trustees were elected unanimously in the AGM:

Graham Lovitt
Roxanne Bonin
Janice Hepworth
Tantara Fox-Stillwell
John Hepworth
Amy Henson
Tony Horton
Ellen Wentworth
Kathryn Chapman
Francesca Goddard
Kim Vaughan
Nat Mason
Gloria Proby

4. Committee roles and responsibilities
To remain the same as 2021/22. There is a potential gap in responsibilities around responding to messaging on social media. ACTION – Tantara and Roxanne to look at what we have on our website and if it's fit for purpose for users. Grahame to speak with the developer around adding a survey to the website.
5. Matters Arising and Action Points not on the agenda
 - 5.1 VHL Alliance Handbook – Kim Vaughan
No changes, no requests or orders for physical copies. **TO BE REMOVED**

6. Financial Report – Graham/Nat/Janice

6.1 Financial Report

Co-op - £47,292.84

PayPal – £2,145.18

Ulster Bank –79.48 Euros

Ireland bank have advised they are closing the bank and therefore the account will be closed by the end of 2022. There are no current regulations in place stating we need to maintain an Irish bank account whilst operating within Ireland. Janice will ensure we are following guidelines and will close the bank account to transfer the money.

6.2 Tax Exemption – Ireland – **TO BE REMOVED**

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

Awareness month has taken place across May 2022, with regular updates on social media. Kayleigh has become more involved in the social media work, and we have seen a steady flow of activity. Roxanne has looked at merchandise and how we can bring back popular products.

8. Website – Graham

Working well and no further issues since upgrade. ACTION - Roxanne is going to look to add the latest 'VHL Stories' to the site.

9. Patient Liaison and Support Group - Nancy

The group agreed to look at facilitating 'wellbeing' sessions for patients. ACTION – Kat to explore options and costings.

10. Life Insurance Update – Kat

This is still progressing.

11. Research Donations – Graham

We have not made any further grant awards or received any requests.

12. Discuss distribution of small grants to individuals in need.

Discussed in 2022 AGM minutes. **TO BE REMOVED**

13. BHD and HLRCC

We have now got a synergy group which is newly formed to bring the VHL alliance, HLRCC family alliance and VHL UK/Ireland and Driven to Cure together into one setting. This will allow each group to understand what research efforts are taking place across organisations and support with funding where it crosses multiple disciplines.

14. Any Other Business

A pilot has been established to look at early detection of cancer in RCC patients through a blood test. John and Janice will update the group on its progress.

ACTION – add Belzutifan as a standing agenda item for future committee hearings.

15. Date and Time of Next Meeting

25th August 2022 at 7:30pm

Signature:

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

Graham Lovitt - Chair

Dated:

November 17, 2022