

Minutes of the Committee Meeting

Thursday 8 June 2023, 7.30 p.m. by Zoom Conference Call

Present:

- Graham Lovitt, Chair, Trustee
- Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
- Janice Hepworth, Co-Chair, Treasurer, Trustee
- Antony Horton, Scientific Advisor, Trustee
- Francesca Goddard, Fundraising Co-ordinator, Trustee
- Kim Vaughan, Genetic Centre Liaison, Trustee
- John Hepworth, Trustee
- Kat Chapman, Trustee
- Tantara Fox-Stillwell, Trustee, Secretary
- Kayleigh Stephens – Committee Member (Website/Social Media)

1. Apologies –Gloria Proby, Ellen Wentworth, Amy Henson, Nat Mason

2. Minutes of the last meeting

The minutes of the last meeting were agreed.

3. Re-appointment of Trustees

All 13 trustees were re-appointed at the AGM held immediately prior to this meeting.

4. Committee Roles and Responsibilities

It was agreed that the following roles and responsibilities will be undertaken in the 2023/24 year:

Graham Lovitt – Trustee, Chair
Janice Hepworth – Trustee, Co-chair, Treasurer
Roxanne Bonin – Trustee, Co-Chair, Marketing & Fundraising Officer
Nat Mason – Trustee, Co-Chair
Gloria Proby – Trustee, Co-Chair
Tantara Fox-Stillwell – Trustee, Secretary
Tony Horton – Trustee, Scientific Advisor
Kim Vaughan – Trustee, Genetic Centre Liaison
Francesca Goddard – Trustee, Fundraising Coordinator
Ellen Wentworth – Trustee, Fundraiser Support
John Hepworth – Trustee
Kat Chapman – Trustee
Amy Henson – Trustee

5. Matters arising and action points not on the agenda

None

6. Financial report

6.1 Bank balances:

VHL Bank Balances

		08/06/2023	02/03/2023	17/11/2022	26/05/2022	24/02/2022
Co-op	Sterling	35,156.86	52,181.88	52,465.61	47,292.84	47,101.02
PayPal	Sterling	2,331.42	1,991.04	413.62	2,145.18	829.08
Ireland	Euro	A/C Closed	A/C Closed	A/C Closed	79.48	93.73

6.2 PayPal Giving Fund – we have an amount pending of £3,281.76.

6.3 Janice will draft a social media post to thank everyone for their donations. **ACTION – Janice**

7. Marketing, Fundraising and Shop Report

7.1 Awareness Month 2023 – was a HUGE success. Thank you to everyone involved. We had lots of stories added to the website, the Warrior Poem, Frankie and Matthew on Anglia News, and Ely Cathedral lit up in blue lights. Stats from social media posts were amazing – the Warrior Poem reached 3,200 people and a Rox's drone video raising awareness in Scotland reached 4K plus.

7.2 Graham reported that Give as You Live donations from Sainsbury's don't come through automatically if using the Firefox browser. Claims can be made later, but it has to be on the original trolley value, excluding any later amendments to the order.

7.3 Merchandise – is to be updated with the new logo. Rox has contacted VHL Alliance to ask why the strapline has been removed – the response was that "it wasn't working". It was agreed that we like it and would leave it on.

7.4 The Charity Ball will be held on 30 September 2023 in Peterborough. 160 tickets have already been sold; we are currently looking for prize donations.

7.5 Georgia McDonough has asked about the possibility of having some wedding favours made with the VHL logo. Tantara will look into this. **ACTION - Tantara**

8. Website

8.1 Kayleigh is running a "Did you know..." series with facts about VHL and asked for ideas/snippets of information that she can use. **ACTION - All**

8.2 Graham reported that the company that has been helping us with the website development is backing off from this type of work, but we should now be able to update ourselves on WordPress.

9. Patient liaison and support group

- 9.1 Rox reported that it might be too much to have an “in-person” support group this year. It was suggested that someone in Scotland/Ireland may like to arrange something and we could help from afar? Another suggestion was to do an online session on belzutifan in early 2024 – we would need to be reactive to any NICE committee decision.
- 9.2 Email communications – Rox is forming an email contact list so that a regular email “newsletter” can be sent out with updates. Not everyone is on social media, so this may reach a larger audience. It would have to be GDPR compliant and recipients would have to opt in to receive email from us.

10. Life insurance update

On hold whilst Kat is working on the belzutifan appraisals. The situation may change if we get access to the new drug via the NHS.

11. Research donations

- 11.1 The £20,000 has now been paid to the Crick Institute. We are delighted with the results coming through from this and previous donations to Cambridge.
- 11.2 Graham asked if there was a way to encourage more people to sign up to the RADAR scheme?

12. Belzutifan update

- 12.1 We are currently in limbo, waiting to hear from NICE. MSD are waiting for NICE to make a decision on whether or not VHL is classed as a rare disease in terms of their drug approvals, or whether it should be appraised on their standard route. We have a catch-up with MSD next week.
- 12.2 Scottish Medicines Consortium – we have an initial meeting next week with the SMC to discuss our role in the Scottish appraisal process. Kat has reached out to a patient in Scotland who is starting belzutifan, but she has not responded as yet.
- 12.3 MP Responses as part of Awareness Month – we received a few responses, one MP has escalated it to ministerial level.
- 12.4 Our website is to be updated as soon as possible with information on the appraisals, but we need to check with MSD next week as to how much information we can release.

13. HLRCC and BHD

- 13.1 BHD Foundation has a symposium running in London in October 2023.
- 13.2 HLRCC – is now being run by the HLRCC Foundation in the USA. It is looking to separate from the VHL Alliance and become a charity in its own right.

14. Any other business

14.1 VHL Medical App – an application has been developed for a specific condition which could be adapted for use by VHL patients. Graham and Kat will follow up on this, as it could be a good use of our funds to support patients.

14.2 Graham has previously mentioned the possibility of our making a donation to the HLRCC website upgrade. This is now being done in-house, so the donation is no longer required. However, they are looking to gain Charitable Status, so could this money (\$1,000) be used for this purpose instead? Proposed Graham, seconded Tony, unanimously agreed.

14.3 Christmas Cards – Kat will try to sell some of our cards via a contact that she has who sells charity cards online.

Date and Time of Next Meeting

Thursday 7 September 2023 at 7.30 p.m. by Zoom Conference Call

Signature: 

Date: 7th September 2023

Graham J. Lovitt – Chair