

Minutes of the Committee Meeting

Thursday 17 June 2021, 7.30 p.m. by 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
- Amy Henson, Social Media Coordinator, Trustee
- Francesca Goddard, Fundraising Co-ordinator, Trustee
- Kim Vaughan, Genetic Centre Liaison, Trustee
- Nat Mason, Co-Chair, Trustee
- John Hepworth, Trustee
- Kat Chapman, Trustee
- Nancy Molyneaux, Patient Support, Committee Member

1. Apologies – Tantara Fox-Stillwell, Gloria Proby, Ellen Wentworth

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 2021/22 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

VHL Alliance Handbook

It was agreed that we would continue to direct patients from our website to the download version of the handbook on the VHL Alliance website.

Kim is to ask the Alliance if they have details of the amendments which have been made in the updated version, so that we can provide an addendum to the existing handbooks that we have in stock to avoid wastage.

New books will be printed for the Genetic Centres.

6. Financial report

6.1 Financial Report

Co-op UK	£40,530.54
PayPal UK	£1,791.52
Ulster Ireland	€122.53

6.2 Tax Exemption – Ireland

We have tax exemption in Ireland. The online forms have now been submitted, there is just the historical “nil” paper returns to be completed. **ACTION - Nat**

6.3 National Westminster Bank Mandate

Mandate forms to be completed to open a new account with the Nat West due to the Co-Op online banking being non-user friendly. **ACTION – Janice**

7 Marketing and fundraising and shop report

7.1 Awareness Month 2021 – went really well, with lots of online activity, a pub quiz and coffee morning. “Takeover Tuesdays” have been popular, where a VHL patient is asked to share their story. This will continue and the stories will be added to the website. Thanks to everyone involved.

7.2 Further pub quizzes are planned – not sure as yet of frequency. A poll is to be put onto Facebook to ask people what events they would like to see and how often they should be held. **ACTION - Frankie**

7.3 Shop – there have been some issues with stock availability, but this should now be sorted. Chris Bonin would like to step down from this responsibility – an advert is to be put onto Facebook asking for a volunteer. Many thanks to Chris for all his hard work and support! **ACTION - Roxanne**

7.4 Give as You Live Storecards – cards which can be pre-loaded with funds are available for major supermarkets which will donate a percentage of shopping bills to the charity. Graham reported that there have been issues with these cards, but that they are now working again.

8 Website

The website is now running smoothly, and the web designer is on hand if we have any problems. An advert for a volunteer to monitor and update the website is to be put onto Facebook. It needs updating regularly to attract people to it. **ACTION - Roxanne**

9 Patient liaison and support group

9.3 The Learning Module that Nancy has developed is now online. Nancy is intending to do more modules when time allows and would like suggestions for topics to be covered.

9.4 Nancy has produced a layout for a wallet/purse card to contain information for emergency use. It will state that the person has VHL and the different types of tumours that affect them so that Emergency Services are aware and can treat accordingly.

9.5 There is some concern that messages are being missed or dropping into spam and consequently are not being replied to. It was agreed that a Messenger group would be set up so that we can communicate more easily and make sure that all requests for support are answered in a timely fashion. **ACTION - Nancy**

10 Life insurance update

Kat is awaiting further information now that she has had both doses of COVID-19 vaccine.

11 Research donations

We currently have £20,000 ring-fenced for Professor Drake at the Crick's Institute, which leaves a further £20,000 available for distribution. It was agreed that this money would be held for the time being, as Professor Drake's project may expand and need further funding.

12 Any Other Business

12.1 BHD and HLRCC – Graham asked that we all stay aware of the fact that the charity is set up to support BHD and HLRCC patients, as well as VHL patients. He was concerned that BHD support was dropping off due to website issues, but this has now been upgraded. He also has a new contact, Dr. Anna Webb, who is getting involved and running webinars with relevant speakers on the site. Three of our trustees are HLRCC patients and although we do not have any BHD representatives, there are some BHD patients registered on our Facebook page.

12.2 We have had an email from the National Institute for Health and Care Excellence (NICE) asking if the charity would like to take part in the "Single Technology Appraisal – Belzutifan for untreated renal cell carcinoma caused by von-Hippel Lindau disease ID3932 – Draft Scope Consultation". It was agreed that we would take part and that John, Tony, Kat, Kim and Frankie would put their names forward as contacts. Kim's brother would also like to be included. Janice to reply to the email with the requested information. **ACTION – Janice**

12.3 There has also been a Facebook post that Graham shared, where the Kidney Cancer Support Network is looking for a VHL patient to take part in the same appraisal. There is a contact address on the posting for anyone interested to contact directly – rose@kcsn.org.uk

13 Date and time of next meeting

Thursday 26 August 2021 at 19:30pm

Signature:



Graham Lovitt - Chair

Minutes prepared by Janice Hepworth

20 June 2021

Dated: June 17th, 2021