

Minutes of the Committee Meeting

Thursday 16 September 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
- John Hepworth, Trustee
- Kathryn Chapman, Trustee

1. **Apologies** – Tantara Fox-Stillwell, Gloria Proby, Nancy Molyneaux

2. **Minutes of the last meeting** were agreed.

3. **Matters arising and action points not on the agenda:**

3.1 VHL Alliance Handbook - 11 hard copies of the new version have been received. It is easier to read than the previous edition, but the changes are too varied and extensive for us to be able to add an addendum to the existing copies that we have. It was agreed that a pdf version would be sent to every Genetic Centre and our website will be updated so that the link takes people to the new edition. **ACTION – Roxanne**

4. **Financial report:**

4.1 Current Balances:

Co-op UK	£43,573.89
PayPal UK	£20.92
Ulster Ireland	€107.98

4.2 Graham requested that in future, a trend is shown for the balances, rather than just a snapshot. **ACTION – Janice**

4.3 Ireland – the online tax returns have all been submitted, there is just the historical “nil” paper returns to be completed. **ACTION – Nat**

4.4 National Westminster Bank Mandate – held over from last meeting. **ACTION – Janice**

5. Marketing, Fundraising and Shop Report:

- 5.1 Roxanne advertised for volunteers to help out with marketing, website management and social media. Two people came forward – Alison McDonough and Hayley Stevens. Frankie and Amy are still happy to contribute to this work.
- 5.2 Kat said that she has a contact in an organisation called “Cards for Good Causes” and may be able to distribute our Christmas cards through this company. Kat to follow up further. **ACTION – Kat**

6. Website:

- 6.1 It was noted that the website has been static for the last 3 months. It needs updating regularly. It is hoped that this will happen once the new volunteers are in-situ.
- 6.2 There is an article on the BHD/HLRCC website (this group now has a new fund-raising manager) about the report to the Bruce Lee Charity. This item could also go on our website.

7. Patient Liaison and Support Group:

- 7.1 Emergency Information Wallet Cards – John has spoken to the printer and 100 of these cards will be printed initially. **ACTION – John**
- 7.2 Amy still has a stock of get-well cards and will advertise their availability. **ACTION – Amy**
- 7.3 Support Group Meetings – no further meetings have been arranged at the moment. It was suggested that if we have a face-to-face meeting in future, the talks could be recorded and put online so that people unable to travel can listen.
- 7.4 Regular coffee mornings – some momentum has been lost with this. There is to be a sub-group meeting of the support team to discuss future arrangements. **ACTION – Support Team Sub-Group**

8. Life Insurance Update – there is no further information on this as yet, but Kat will chase and ask if belzutifan will have an impact on life insurance availability.

9. Research Donations – Janice to contact Professor Drake to ask if there is any update on his research work and when the first invoice will be raised.

10. Any Other Business:

- 10.1 Tony commented that he has come across an organisation called “Jeans for Genes” which raises money to fund projects that make a tangible difference to the lives of those living with a genetic disorder. He will investigate further. **ACTION – Tony**
- 10.2 Belzutifan NICE Appraisal – Kat shared the NICE project plan and updated the committee on the progress to date. We are awaiting a date by which our written statements (from the charity, patient representative and patient expert representative will need to be submitted to the NICE Appraisal Committee. To support these statements, a survey has been designed and will shortly be put on as many social media

channels as possible to ensure that we get a good response rate. August 2022 is currently being advertised as the planned approval date. The UK approval process is only currently for RCC Kidney cancer, but new trials are taking place internationally with people who suffer from PNETS, PGL and Pheos.

10.3 The VHL Alliance held a “Town Hall” meeting last weekend and the video of this is now available on YouTube.

10.4 It was agreed that an update from the sub-groups (currently the NICE Appraisal sub-group and the Support sub-group) would each have a specific agenda item on future committee meetings for updates to be shared with the full committee.

11. Date and Time of Next Meeting – 25th November 2021 at 7.30 p.m. by Zoom online call.

Signature:

Dated: 16 September, 2021

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

Graham Lovitt - Chair