

Minutes of the Annual General Meeting

VHL UK/Ireland Committee - Thursday 30 May 2019, 7.00 p.m. by Skype Conference Call

Present: Graham Lovitt, Chair, Trustee
Janice Hepworth, Co-Chair, Secretary, Trustee
Nat Mason, Co-Chair, Treasurer, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Tony Horton, Trustee, Scientific Advisor
John Hepworth, Trustee

1. **Apologies** – were received from trustees Amy Henson, Gloria Proby and Ellen Wentworth and member Dara Jayasundaram.

2. Trustees

The following trustees were elected unanimously:

Graham Lovitt
Nat Mason
Roxanne Bonin
Janice Hepworth
John Hepworth
Amy Henson
Elaine Graham
Gloria Proby
Tony Horton
Ellen Wentworth

3. **Minutes of the Meeting held 24 May 2018** were agreed and signed.

4. Presentation of Accounts

The accounts were reported to the meeting, approved unanimously and Nat was thanked for his work.

5. Chair's Annual Report – need this from GL

6. The charity has had a very successful year in its core objectives of raising funds to grant awards for research and to provide patient support.

Donations both large and small continue to be made to the charity from individuals and events.

On the 30th June 2018, a VHL UK/Ireland support and information meeting was held in the

Bateson Centre at the University of Sheffield. The tiny zebrafish embryo is used in this exciting research into the workings of the VHL gene.

The annual Patient Support Group was held at Addenbrooke's, Cambridge on Saturday 17th November 2018 with over 35 patients, family members and genetics staff attending.

The charity provided funding to support a person with the online Wellness Coaching Program organised by the VHL Alliance.

The charity continues to provide a patient support service by telephone. It supports the hosting of websites for both the charity www.vhl-uk-ireland.org and the HLRCC Family Alliance www.hlrccinfo.org. The charity paid for the latter website to be converted to WordPress. The HLRCCFA is a project of the VHL Alliance.

The charity has made two grant awards of £40,000 each to the Genetic Centre at Addenbrooke's, Cambridge under the stewardship of Professor Eamonn Maher to support (1) a VHL patient registry and surveillance project; and (2) a VHL gene analysis of the 100,000 genome project data. The second project was initially funded by the VHL Alliance and our grant award enables its continuation to completion.

7. Any Other Business

None.

Signature: 

Graham Lovitt - Chair

Dated: June 11th, 2020