



Minutes of the Annual General Meeting

VHL UK/Ireland Committee - Thursday 11 June 2020, 7.00 p.m. by GoToMeeting 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
John Hepworth, Trustee
Kathryn Chapman – Trustee
Francesca Goddard

1. **Apologies** – were received from trustees Tony Horton, Gloria Proby, Ellen Wentworth and Nancy Molyneaux.

2. Trustees

The following trustees were elected unanimously:

Graham Lovitt
Nat Mason
Roxanne Bonin
Janice Hepworth
John Hepworth
Amy Henson
Gloria Proby
Kathryn Chapman
Francesca Goddard

The following trustees were not present at the meeting and will be contacted by email to ask if they wish to continue:

Tony Horton
Ellen Wentworth

3. **Minutes of the Meeting held 30 May 2019** were agreed and signed.

4. Accounts

The accounts for 2018/19 have been submitted to the charity commissions in both England and Wales, and Ireland. Nat thanks John and Janice for arranging the independent review. The 2019/20 accounts will be submitted at a later date. Thanks were also given to Nat for his work as Treasurer. He is stepping down from this role as soon as a new secretary is appointed, although he will continue to be a Trustee. Janice will take over the role of Treasurer.

5. Chair's Annual Report

The charity has had another successful year of meeting its charity objectives.

The charity continued to support patients through its website <http://vhl-uk-ireland.org/>, by freephone telephone and social media of Facebook and Twitter. The fifth annual patient support meeting was organised at Birmingham on the 16th November 2019.

Many individuals raised money through their fundraising events and made individual donations. Donations were made through birthdays on Facebook, purchases through store cards, Give as You Live and Amazon Smile. The online shop continued to generate trading items through the sale of VHL-branded items.

The charity has now disbursed 75% of its grant award of £40,000, committed in 2017/18 to Professor Eamonn Maher to fund a project study at Cambridge Medical Genetics Department over the next 2 years. The project is titled: "Registry for Von Hippel-Lindau disease and related renal tumour predisposition syndromes".

The second project to support Prof. Eamonn Maher's team to extract information from the data provided by the 100,000 Genomes Project was agreed, to a value of £40,000 and commenced in September 2019. This project continues the funding originally provided by the VHL Alliance.

The total funding for these two projects is ring-fenced in the existing funds held by the charity.

VHL Awareness Month took place in May 2019. With the outbreak of COVID-19 all face-face meetings are currently suspended and have been replaced with on-line quizzes and coffee meetings

The charity's income for this coming year is likely to be reduced as fundraising activities are somewhat curtailed because of COVID-19 and there is a financial impact on the public reducing donations. The charity has minimum overheads and sufficient reserves so the only effect will be a reduced level of funding available for any grant awards that are made in the future.

6. Any Other Business

None.

Signature: 

Graham Lovitt - Chair

Dated: June 11th, 2020