



## **Minutes of the Trustee Meeting**

### **VHL UK/Ireland Committee**

**Thursday 24 May 2018, 7.15 p.m. by Skype Conference Call**

**Present:** Graham Lovitt, Chair, Trustee  
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee  
Janice Hepworth, Co-Chair, Secretary, Trustee  
Tony Horton, Trustee, Scientific Advisor  
John Hepworth, Trustee  
Amy Henson, Trustee, Social Media Co-ordinator

1. **Apologies** – were received from Gloria Proby and Ellen Wentworth.

2. **Election of Officers and Trustees for the year 2018/19:**

Graham Lovitt, Chair, Trustee  
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee  
Janice Hepworth, Co-Chair, Secretary, Trustee  
Nat Mason, Co-Chair, Treasurer, Trustee  
Gloria Proby – Co-Chair, Trustee  
Tony Horton, Scientific Adviser, Trustee  
Amy Henson – Trustee, Social Media Co-ordinator  
John Hepworth - Trustee  
Elaine Graham – Trustee  
Ellen Wentworth - Trustee

3. **Minutes of the Last Meeting** – were agreed and signed.

4. **Matters Arising and Action Points not on the Agenda**

4.1 Membership Register - conforms with the new GDPR regulations, but these regulations need to be kept in mind should we decide to set up a full mailing list in future.

4.2 Old £10 notes end of circulation dates – this has been done.

4.3 Gift Aid – the claim has not been done yet but will be completed in the next few weeks. **ACTION - Graham**

4.4 Charity Pots – these have been advertised and a further advert will go out shortly.  
**ACTION - Amy**

4.5 Visibility of Shop Income – John to liaise with Nat so that an infographic can be put on the website. It was also discussed that we could create a timeline showing the history of the charity and funds raised over time. **ACTION – John, Nat, Roxanne**

## 5. Financial Report

5.1 The current balance at the Co-operative Bank is £75,327. There is also €2,174 in the Ulster Bank.

5.2 £40,000 of this money is now ring-fenced for the Cambridge project.

5.3 The possibility of moving some funds into a savings account is to be investigated. Janice will have a look at the COIF (Charities Official Investment Fund) Deposit Account. **ACTION - Janice**

## 6. Marketing, Support Groups and Shop Report

6.1 VHL Awareness Month – May 2018. This event is going well and there has been a considerable amount of activity on the website and Facebook page. The “Warrior” post reached 9,000 people and the video had 5,500 views. Amy is to give this one final push as the month comes to an end. Our posts reached an amazing 29.5K people in May, up by 23.7K.

6.2 VHL Alliance alignment – unfortunately didn’t work out as hoped.

6.3 Roxanne asked for approval to buy a gift for the web-designer who has spent about 6 weeks designing artwork for no fee. Agreed £50 gift voucher, with our thanks.

6.4 GDPR – the new regulations and the effect on the charity were discussed. It was agreed that we are within the regulations as far as emailing people is concerned as this is mainly concerned with the support group arrangements. However, we will email everyone and ask if they are happy to continue receiving information in this way. We also have a list for the Genetic Centres, but this is covered by the Legitimate Interest rule. Roxanne will put a Privacy Notice on the website.

## 7. Research Donations:

7.1 The Cambridge University Hereditary Renal Tumour Syndrome Registry Project is now up and running and we have agreed the Grant Award of £40,000 over two years.

7.2 There is also a request from Professor Eamonn Maher that we fund a PHD student to do further research once the above project has ended.

## 8. Support Group Meetings

8.1 Arrangements for the Addenbrooke's Hospital support group are going well, but we can't confirm the booking of the room until nearer the time. Roxanne is looking for alternative accommodation as a back-stop.

8.2 Sheffield Research Day – we now have 20 names on the list and arrangements are going well. Roxanne will bring pins badges, lanyards etc.

## 9. Fundraising and Events

9.1 Amazon Smile and Facebook Charitable Giving Trust – Janice to look into getting the charity registered for Amazon Smile donations; Roxanne will look into the Facebook Charitable Giving Trust. **ACTION – Roxanne and Janice**

## 10. Any Other Business

10.1 VHL Handbooks – is it possible to obtain feedback from the Genetic Centres on the distribution of handbooks and ask if they need any more copies? **ACTION - Roxanne**

## 11. Date and Time of Next Meeting

11.1 Thursday 2 August 2018 at 7.30 p.m. by Skype.

Signature:  \_\_\_\_\_

Date: 3rd November 2018

Graham J. Lovitt – Chair