



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 22nd February 2018, 7.30 p.m. by Skype Conference Call

Present: Graham Lovitt, Chair, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Amy Henson, Trustee
Anthony Horton, Trustee, Scientific Advisor
Nat Mason – Co-Chair, Treasurer, Trustee

Apologies – were received from Gloria Proby, Janice Hepworth, John Hepworth, Ellen Wentworth

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

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

2.1 Membership Register – this has now been put onto Dropbox. Some information has now been updated – please can everyone else check that their information is up to date? **ACTION ALL.**

2.2 Paper sponsorship forms and the new gift aid rules – this hasn't been done as yet. John will email a template of the necessary wording to Roxanne. **Complete**

2.3 Old £10 notes – Amy to reschedule Facebook posts to include the end of circulation dates for old £10 notes. **ACTION - Amy**

3. **Financial Report**

3.1 Financial accounts were signed off.

3.1.1 2017: £15,500k in, £4,500 payments

3.1.2 Republic of Ireland –1500 Euros Ireland. Payments £600. Charity size issue resolved

3.1.3 Today we have just over £72000 in Co-op. Paypal account £1631. Ireland 1 euro. Ulster **TBC Action – Nat**

3.1.4 Need to change online email address with Ireland charity commission. **ACTION – Nat**

3.2 The Co-operative bank balance now stands at almost £70,000. In region of £80,000 carry risk of limit for Co-op

3.3 Graham will look at Gift Aid before end of Financial year. Had a lot less paper donations. **ACTION - Graham**

3.4 Amy to promote charity pots. **ACTION – Amy**

4. **Marketing and Shop Report**

4.1 Roxanne shared outcome of recent meeting with VHL Alliance, where they discussed collaborating for VHL Awareness Month, possibility of sharing content, inclusion of UK/Ireland patients on Facebook Live via 'The Mighty', idea of regional leaders and involvement with 'MY VHL' patient study. **Action – Roxanne**

4.2 Graham asked if we give enough visibility to the amount raised through the shop? Roxanne will design an info-graphic for the website. John could perhaps help with this once the 2017 figures are finalised. **ACTION – Roxanne and John – carried over**

4.3 Discussed possibility of a bundle to sell to encourage more sales. **Action – Roxanne**

5. **Research Donations:**

5.1 Graham has contacted Eamonn Maher however has not seen a reply. Agreed it would be beneficial to get this started this financial year and that we should keep in communication with Eamonn Maher. **ACTION – Graham**

5.2 We noticed with Charity Commission, when making a donation to an org that is not a charity, need to follow certain conditions. **ACTION – Graham to follow up.**

5.3 Addenbrookes research update -. We need to make sure that our involvement is advertised to fund raisers. Graham got two names he forwarded and also a contact in US. **Complete**

5.4 HLRCC website – would be €350 plus €90 to convert whole website. Website is now live. As part of supporting HLRCC within VHL UK/Ireland, this is ongoing support for the website. **Complete**

6. **Support Group Meetings**

6.1 Next Support Group provisionally booked for Saturday 17th November at Addenbrooke's Hospita. Roxanne advised venue cannot be firmed up until April, will take provisional registrations of patients until then. Catering likely to be more than

previous support groups but it was agreed this was acceptable. Roxanne to update Charity on progress. **ACTION – Roxanne**

6.2 Roxanne will do a blog about setting up support groups in other areas if anyone wants to organise an event in other areas. **ACTION – Roxanne**

6.3 Sheffield University Patient Research Day has had good response, over half of places now booked. Roxanne to keep promoting. **Action – Roxanne**

6.4 There has been a request for a child-friendly fun-day to be held. This would be an informal support group aimed at families with young children at a play centre of some kind. To be considered in 2018, maybe during the summer holidays. **Not followed up**

7. Fundraising Events

7.1 Covered throughout meeting

8. Any Other Business

9. Date and Time of Next Meeting

9.1 Next meeting will be Annual General Meeting

9.2 Graham enquired if anyone wanted to be chair

9.3 AGM will be: 17 May 2018, 7.00 p.m. by Skype Conference Call, which will be followed by the Trustee meeting at 7.30pm directly after.

Signature: _____



Date: 3rd November 2018

Graham J. Lovitt – Chair