



Minutes of the Trustee Meeting

VHL UK/Ireland Committee

Thursday 23 November 2017, 7.30 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
Nat Mason – Co-Chair, Treasurer, Trustee
John Hepworth, Trustee
Amy Henson, Trustee

1. **Apologies** – were received from Gloria Proby and Ellen Wentworth.
2. **Minutes of the Last Meeting** – were agreed and signed.
3. **Matters Arising and Action Points not on the Agenda**
 - 3.1 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.**
 - 3.2 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. **ACTION – John and Roxanne**
 - 3.3 Old £5 notes and £1 coins – Amy to reschedule Facebook posts to include the end of circulation dates for old £5 notes. **ACTION - Amy**
 - 3.4 Child-Friendly Christmas Cards – to be considered for 2018.
 - 3.5 Old £5 notes – it was advertised that we will take any old-style £5 notes as a donation to the charity. There is a similar situation with £1 coins which go out of circulation on 13 October 2017. **ACTION - Janice**
4. **Financial Report**
 - 4.1 The Co-operative bank balance now stands at almost £70,000.
 - 4.2 The current balance at the Ulster Bank is €2,653.64

4.3 Nat has been looking into arranging charity status with the Revenue Commissioners in Ireland and now has clarity on the requirements. Costs for such items as printing handbooks and the ring central telephone service are to be split between the two branches of the charity.

4.4 Information for the 2017 accounts for the UK Charity Commission is to be sent to John as soon as possible.

5. Marketing and Shop Report

5.1 Amy is still publicising the shop on social media. We now have the new “Warrior” style key rings. T-shirts and pin badges are to be re-stocked.

5.2 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**

5.3 Roxanne is looking to touch base with the VHL Alliance to share ideas and look for new ways of marketing the charity. **ACTION - Roxanne**

6. Research Donations:

6.1 It is looking as though the research project at Addenbrookes Hospital will be going ahead. Graham will post on Facebook for families to come forward if they are willing to take part. We need to make sure that our involvement is advertised to fund raisers.

6.2 Graham asked if we could support the upgrade of the HLRCC website, which is 7-8 years old and in need of refreshing. It was unanimously agreed that we would support this project to a value of €350.

7. Support Group Meetings

7.1 The Support Group meeting in Glasgow was a huge success and saw the biggest attendance so far. Many thanks to Roxanne for organising the day.

7.2 The 2018 Support Group will possibly be at Addenbrookes Hospital. There is the possibility that a drug company looking to set up trials will be involved in the day. The date will again be during October and November.

7.3 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**

7.4 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.

8. Fundraising Events

- 8.1 Masquerade Ball – about £3,000 was raised at the ball – another huge success and an excellent evening! Thanks to Roxanne and Vixstars for organising this, also to everyone who helped with the evening.
- 8.2 We need to try to get involved with some of the bigger stores (Tesco, Waitrose, M&S etc.) with their charity of the month promotions.
- 8.3 Charity Boxes/Buckets – fundraising by this method is quite slow, unless they are used as part of an event (runs, walks etc.).
- 8.4 Amy's mum is having a bake sale at work to raise fund – thank you Amy's mum!
- 8.5 If anyone has any ideas for fundraising, please let Roxanne or Amy know.

9. Any Other Business

- 9.1 Addenbrookes Hospital – improvements are being made to their screening process and they now offer brain and spine MRI scans every three years. Graham reported that the HLRCC Family Alliance has recently taken a strong view in favour of patients against clinicians when deciding when screening should start for children at risk of HLRCC. The NIC in America tests from 8, but some countries are trying to get this put back to age 16-18; the argument being that there is no need to screen people if they aren't showing signs of HLRCC.

10. Date and Time of Next Meeting

- 10.1 22 February 2018, 7.30 p.m. by Skype Conference Call

Signature:  _____

Date: 3rd November 2018

Graham J. Lovitt – Chair