



Agenda

VHL UK/Ireland Committee

Thursday 25th February 2021, 7.30 p.m. by GoToMeeting Conference Call

Present:

Graham Lovitt, Chair, Trustee
Roxanne Bonin, Co-Chair, Marketing & Fundraising Officer, Trustee
Janice Hepworth, Co-Chair, Trustee
Tantara Fox-Stillwell, Secretary, Trustee
Antony Horton, Trustee
Frankie Bryant, Trustee
Nancy Molyneaux, Patient Support
Kathryn Chapman, Trustee
Nat Mason, Co-Chair Trustee
John Hepworth - Trustee

1. Apologies

Kim Vaughan, Trustee, Gloria Proby

2. Minutes of the last meeting

Minutes of the last meeting approved.

3. Matters Arising and Action Points not on the Agenda

3.1 VHL Alliance Handbook – Roxanne

Awaiting the new copy of the handbook. We still have around 50 copies of the old booklets left. Group agreed that the old copies can still be circulated with an addendum highlighting the changes.

3.2 Cancer Genetics Group Meeting – Tony

This has been superseded. **ITEM TO BE REMOVED.**

3.3 Dropbox name and address file to be updated - all

ITEM TO BE REMOVED. All changes to be sent to Graham due to dropbox issues.

4. Financial Report – Graham/Nat/Janice

4.1 Financial Report

PayPal	GBP 40,274.07
Co-op UK	GBP 29,504.48
Ulster Ireland	Euro 1073.53
Paypal Ireland	Euro 0

Nat has a few returns to complete for tax returns and then we will be up to date. There may be changes to Ulster Bank, which Graham has been contacted about. No actions needed to be taken currently.

Janice has been looking at moving the banking from Co-op to NatWest. Group agreed they were happy for Janice to look into this further.

Charity Regulatory Authority will be seeing some changes due to some of the voluntary actions becoming mandatory. Further involvement is needed from Ireland to help maintain a collaborative approach and increase fundraising. The group agreed that we could advertise a role to join the committee and open it up to Ireland residents.

4.2 Tax Exemption – Ireland

Not discussed

4.3 Co-op Bank Mandate – Graham

Not discussed

4.4 Charity Commission Financial Review – John

TO BE REMOVED FROM THE AGENDA.

5. Marketing, Fund-Raising and Shop Report – Roxanne, Amy and Chloe

Marketing and shop ongoing as normal. Awareness month is upcoming and Roxanne is looking at what the alliance will be doing.

Frankie has set up an excel for fundraising activity. Looking at 'Miles in May' as a possible fundraising opportunity. Many people are still fundraising privately and making contact once the money has been raised. Frankie and Roxanne have been making contacting with organisers to provide them with certificates and obtain further information for social media posts.

6. Website – Graham

The new website has been created, just a few bits which need amending and added ready for it to go live. Once the website is approved, we will receive the invoice from the web creator.

7. Patient Liaison and Support Group - Nancy

Nancy provided a PowerPoint presentation on VHL providing key facts and information in an interactive way. Once completed this can be added to the new website.

Nancy has been looking into 'Emergency Cards' which has information about VHL in cases of emergency for healthcare workers or family and friends. Currently these were only available

from the VH Alliance, however they are happy for us to replicate for the UK. Nancy will start designing these and look into printing options.

Patient support has been quiet with a few people making contact through the Facebook page.

8. Life Insurance Update – Kat

No update. Waiting to have second jab and then look back into this.

Kat has been in contact with a VHL patient who can provide support and wellbeing sessions to patients. The group agreed that this is something they would like to look at. **ACTION** – Kat to circulate video of possible sessions to see if they need to be more bespoke for VHL patients.

9. Research Donations – Graham

Graham is having issues communicating with Barts Hospital. Graham has made further contact with them last week.

Graham to contact Eamon Maher to see if there is any further work he is undertaking which would benefit from a grant award. Potential to offer £40/50,000.

10. Any Other Business

Plans for support group still ongoing but due to covid restrictions we have been unable to look forward at our plans. Awareness month is coming up and it may be that we want to look at organising a virtual coffee morning in May.

HMRC.org.uk website upgrade has been agreed and now a secured site.

Drug trial Belzutifan is currently underway in US and is currently under approval. Graham to contact Eamon Maher to look at how this would be processed in the UK.

Group agreed to active role in maintaining the website and keeping it a 'live' page.

Graham has been following up as to why the BHD Syndrome website has not been upgraded in content for several years and is pleased to have announced in the Facebook group that Dr Anna Webb has joined the Myrovlytis Trust and BHD Foundation as Charity Manager.

11. Date and Time of Next Meeting

AGM and Committee Meeting 19:00 11th June 2021

Signature:  _____

Dated: June 11th, 2020

Graham Lovitt - Chair