



Minutes

VHL UK/Ireland Committee

Thursday 7th September 2023, 7.30 p.m. by Zoom Conference Call

1. Apologies

Francesca Goddard, Nancy Molyneaux.

2. Minutes of the last meeting

Minutes approved by the group. AGM minutes uploaded onto the website and all committee meetings up to February 2023 added.

3. Matters arising and action points not on the agenda

None to note.

4. Financial Report – Janice

Co-op	£45,806.27
PayPal	£547.60

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

- The charity ball to take place at the end of September. Over 240 people in attendance on the evening. Merchandise to be sold at the event, there is stock still to be sold before new merchandise is designed.

6. Website – Graham

Belzutifan update has been uploaded onto the website. No errors with the website currently.

7. Patient Liaison and Support Group – Nancy

No update for this meeting.

8. Life Insurance Update (on hold)

To remain on hold until Belzutifan update.

9. Research Donations – Graham

Further research with Prof William Drake. Initial proposal has been provided to the committee. Awaiting costings breakdown and next steps.

10. Belzutifan update

Website has been updated with the most up-to-date detail on Belzutifan. Scotland is likely to be published this month. Our meeting has taken place this week and the outcome is likely to be published in the next month. VHL reps needed for media enquiries around week commencing 9th October. Committee meeting in November and a decision date is likely to be end of January.

Update October 2023 – Belzutifan has now been approved for use in Scotland.

11. BHD and HLRCC

Graham to attend two-day BHD event in London later this year. HLRCC is now HLRCC Foundation. New website developed and Facebook group expanding in numbers.

12. Any Other Business

Phone app – still to be progressed. Nat to pick this up from Kat. Meeting to be arranged with developer to understand how we can create a patient focused app.

13. Date and Time of Next Meeting

23rd Nov 2023 – 19:30pm

Signature:

Dated:



Graham Lovitt – Chair

November 23rd, 2023