



Minutes

VHL UK/Ireland Committee

Thursday 21st August 2025, 7.30 p.m. by Zoom Conference Call

Attendees – Janice Hepworth (Chair), Graham Lovitt, Tantara Fox-Stilwell, Kat Chapman, Kim Vaughan, Nat Mason, Mark Lodge, John Hepworth, Georgia Howe, Roxanne Bonin, Francesca Goddard, Tony Horton.

1. **Minutes of the last meeting** – Approved appending any further communication from the committee.
2. **Matters arising and action points not on the agenda**
3. **Financial Report – Janice**

Co-op	£59,144.08
PayPal	£1009.46
Ireland	97.80

£41,000 ring-fenced for Crick Institute belzutifan project.

Easy fundraising - £69.27 raised this quarter. Roxanne to look at posting more about it on social media.

4. **Marketing, Fund-Raising, and Shop Report – Roxanne**

Fundraising – great fundraising taking place, but the charity doesn't have a process to ensure certificates goes out and acknowledged on social media. Conversations ongoing on how to build a process around this. Would it help to register on Go Fund Me to be able to identify who the donations have come from? (To monitor).

Marketing – need to build this into the strategy and look at potential volunteer roles.

5. **Website – Graham**

Roxanne and Mark discussed last week. Ongoing maintenance was discussed and needing an easy interface so we can upskill members to help with this work.

Mark took the group through the proposal. Roxanne to put comms out on the group WhatsApp to ask for volunteers, once timelines have been identified.

6. Patient Liaison and Support Group – Nancy

Tantara and Kim to contact Oxford re potential support group. To set up meeting in September with them to find out more and how the charity can support.

7. Life Insurance Update (on hold until 2026) – Kat

No further updates. Kat to progress this over the next few months.

8. Research Donations – Graham

No further updates. £41,000 ringfenced for Belzutifan research (Crick Institute).

9. Belzutifan update

Irish appraisal is due to be presented to the health products regulatory authority in October.

10. BHD and HLRCC

Tony gave update due to changes in this area.

11. Any Other Business

Appointment of a new chair – advertisement will need to take place shortly to appoint a new chair. A roles and responsibilities document will need to be drafted to support this.

12. Date and Time of Next Meeting

Thursday 20th November 2025, 7.30 pm by Zoom Conference Call

Signed:

Roxanne Bonin – Co-Chair

Dated: 20/11/2025