



Minutes

VHL UK/Ireland Committee

Thursday 7 March 2024, 7.30 p.m. by Zoom Conference Call

1. Attendees

Attendees: Graham Lovitt (Chair), Kathryn Chapman, Kim Vaughan, Janice Hepworth, John Hepworth, Roxanne Bonin, Amy Henson, Tony Horton, Nat Mason, Joyce Bonin, Freya Fox-Stilwell, Francesca Goddard, Nancy Corbetta, Ella Fox-Stilwell.

The Chair extended a warm welcome to all of our new committee members.

2. Minutes of the last meeting

Committee members in attendance agreed to the minutes.

3. Matters arising and action points not on the agenda.

Potential HLRCC Projects – to be carried over. **ACTION** – Graham and Tony

4. Financial Report – Janice

	7 March 2024	23 November 2023
Co-op	£69,680.80	£58221.35
PayPal	£1,000	£913.62

Janice is looking to open a COIF deposit account, which is specifically designed for charities and has shown a good return over the last few years. Signatories to be Graham, Janice and Tony.

Committee reviewed the year end accounts for April 2023. This can be included in the minutes for the AGM.

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

Marketing – the email database is now building up and a belzutifan update has been sent out. The charity is not currently registered with the Information Commissioners Office for GDPR, as up until now we have not maintained a database of personal information. Janice to check this out and register if necessary. **ACTION** - Janice

The new committee members agreed to discuss their ideas for marketing option. **ACTION** – Marketing Team

The charity will celebrate its 10th Anniversary in 2025 (incorporated with the Charity Commission in February 2015) and this is to be celebrated. “Take 10” was suggested as a theme – encourage everyone to take 10 minutes, walk 10 minutes, walk 10 miles etc. To be discussed further.

Shop – Joyce has done a stock take and new stock is needed urgently. Ideas for merchandise welcome please.

ACTION – Tantara to build a key roles and responsibility list so we can see what gaps we have. UPDATE: Attached for discussion.

6. Website – Graham

GDPR statement to be updated as necessary once we have details from the ICO.

7. Patient Liaison and Support Group – Nancy

There has been a significant misunderstanding re the Young People’s Support Meeting in Munich which is taking place in May. In future, we need to ensure that we have everything in writing and also ensure that we do not use a “first past the post system” to select delegates, a ballot would be fairer.

It has been suggested that we run our own UK/Ireland event for young people. The amount of work required (and regulations to be met) should not be underestimated if this is to go ahead.

Patient Event 2024 – volunteers required please to arrange this. A family event (possibly over 2 days) was suggested, but as above, this needs to be seriously considered in terms of safeguarding for young people. Venue should be in the north of England this time.

List of Genetic Centres – Kat is still pulling together a contact list for every UK/Ireland Genetic Centre **ACTION** – Kat.

8. Life Insurance Update

The charity has been invited to send a representative to a meeting in London on 15th May 2024 re genetic testing and insurance cover. Kat is hoping to attend.

9. Research Donations – Graham

The RADAR scheme which we support is currently being advertised further by Prof. Maher. IT was agreed that we would send a newsletter out asking patients to sign up for the scheme, but this will be held over until we can also include an update on belzutifan. Graham to check our website for up-to-date contact information re RADAR. **ACTION** – Graham. Graham is also pushing Prof. Maher to join a similar group for HLRCC patients.

10. Belzutifan update

Committee decision from 15th February 2024 has been delayed and we are still awaiting the outcome.

11. BHD and HLRCC

An HLRCC Patient Information Leaflet is being produced by the British Association of Dermatologists.

The HLRCC Alliance has now been formed to work alongside the HLRCC Foundation. An online symposium is to be organised.

12. Any Other Business

- Phone app – Nat has followed up with the contact on this, but has not yet received a response.
- Cambridge Event – we have been invited to attend a university training day at Addenbrookes Hospital on 4th May 2024. We would have a “stall” for the charity and would have the opportunity to discuss VHL with trainee medical students. John, Janice, Kat and Frankie to attend. It was agreed that travel expenses would be paid.
- Roles and Responsibilities Spreadsheet – this was circulated to all members. Kim has been added to “Liaison” and Tony is to be the deputy contact for research issues. Rox asked that someone else should be the lead for events – we maybe need someone with better knowledge of social media.

13. Date and Time of Next Meeting

Thursday 13th June 2024 – AGM at 7pm, followed by Committee Meeting.

Signature:

Dated: 13th June 2024



Graham Lovitt - Chair