



## **Minutes of the VHL UK/Ireland Committee**

**Thursday 22 November 2022, 7.30 p.m. (online by Zoom)**

### **1. Apologies**

Nat Mason, Francesca Goddard, Kathryn Chapman, Gloria Proby, Tantara Fox

### **Attendees**

Graham Lovitt, Janice Hepworth, John Hepworth, Roxanne Bonin, Kim Vaughan, Amy Henson, Tony Horton, Nancy Molyneaux.

### **2. Minutes of the last meeting were agreed.**

### **3. Matters Arising and Action Points not on the Agenda: None**

### **4. Financial Report – Janice**

#### **4.1 Bank Balances**

#### **VHL Bank Balances**

|         |          | 17/11/2022 | 26/05/2022 | 24/02/2022 | 25/11/2021 |
|---------|----------|------------|------------|------------|------------|
| Co-op   | Sterling | 52,465.61  | 47,292.84  | 47,101.02  | 45,790.37  |
| Paypal  | Sterling | 413.62     | 2,145.18   | 829.08     | 159.57     |
| Ireland | Euro     | A/C Closed | 79.48      | 93.73      | 107.98     |

4.2 Ireland Bank Account – this account has now been closed and the remaining balance of €65.23 transferred to Pagecrafted, the company which maintains our website.

4.3 We still have not received the invoice from the Crick Institute for the Grant Award money of £20,000. This is ring-fenced from the amounts shown above.

4.4 Accounts to 5 January 2022 are ready to go to the independent examiner.

4.5 Graham has submitted Gift Applications to HMRC.

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

5.1 Roxanne has been in contact with the new Marketing Manager at the VHL Alliance.

5.2 Social Media – Roxanne is to advertise for help with social media posts. Kayleigh is still recovering from her operation, Amy offered to step in to help.

5.3 Two main fundraising events ongoing at the moment – Sophie Sibling is doing the 3 Peaks' Challenge and Aaron ?? is holding a concert in London.

5.4 Christmas Cards – we are looking at doing Black Friday Deal and also taking some cards to the Patient Event in Cambridge.

5.5 Janice queried an invoice received from Ebay – Roxanne to check if this needs to be paid, or if it will be taken from sales money received. Not many sales going through at the moment, Amy suggested Vintage and Graham suggested Facebook Marketplace as possible alternatives.

**6. Website – Graham. Nothing to report.**

**7. Patient Liaison and Support Group – Roxanne**

7.1 Nancy thanked everyone for notifying her when emails arrive as she doesn't seem to receive them as they come in. She has been replying to emails, but nothing to report.

7.2 Support Group Cambridge – agenda and catering finalised, an email will be sent to attendees this weekend with directions and car parking information.

**8. Life Insurance Update – Kat**

No further updates.

**9. Research Donations – Graham**

9.1 No donations have been made recently – still waiting for invoice from Crick Institute.

**10. BHD and HLRCC – nothing to report.**

**11. NICE Appraisal Sub-Group & Support Team Sub-Group**

11.1 We are currently awaiting information from NICE re the routing decision (i.e. MSD has applied to NICE for the belzutifan appraisal to be done via the HST route for rare diseases).

11.2 The decision made by NICE only covers England. Scotland has its own process, Wales and Northern Ireland usually follow the NICE decision.

11.3 VHL Alliance is currently pushing for the EU to progress its approval process.

**12. Any Other Business**

11.1 Eurordis Membership – now approved. Graham will provide a copy of the approval for a social media post to be published.

- 11.2 Visit to Crick Institute – we had a very informative visit to the Crick Institute last month and have asked them to send a summary of the research that they are doing so that we can make people aware of their work. It's a very impressive set-up!
- 11.3 John has a telephone meeting tomorrow with the Wellcome Sanger Institute re his experience of renal cell carcinoma. They are looking to get approval for the use of an existing cancer drug for RCC.
- 11.4 Graham has been in touch with Josh Mann of the VHL Alliance re changing VHL testing guidelines. There is another gene, which when mutated, can cause VHL-like symptoms. Josh responded that it is too early to change the guidelines, but that we should be raising awareness. Graham will speak to Prof. Eamonn Maher at the patient event.

**13. Date and Time of Next Meeting**

**Thursday 16 February 2023, 7.30 p.m. (later postponed to Thursday 2 March 2023, 7.30 p.m.)**

Signature:

Dated: 2nd March 2023

A handwritten signature in black ink, appearing to read 'G. Lovitt'.

Graham Lovitt - Chair