



von Hippel-Lindau Disease
THE CURE FOR CANCER IS IN OUR GENES

ANNUAL ACCOUNTS
ANNUAL CHARITY REPORT
&
INDEPENDENT EXAMINER'S REPORT

Year Ended 5 April 2023



Receipts and Payments Account (UK) for the Year Ended 5 April 2023

05 April 2022		05 April 2023	
£		£	£
	Receipts:		
17,977	Donations (Inc. Gift Aid)		7,909
154	Trading Activities		201
<u>18,131</u>			<u>8,110</u>
	Payments:		
-	Grants and Donations	20,086	
-	Patient Support	787	
144	Subscriptions	194	
621	Website and Postage	445	
36	Fundraising Charges	2	21,514
<u>801</u>			
<u>17,330</u>	Net Receipts/-Payments	<u>-</u>	<u>13,404</u>
30,991	Opening Balance		48,321
<u>17,330</u>	Net Receipts/-Payments	<u>-</u>	<u>13,404</u>
<u>48,321</u>	Closing Balance		<u>34,917</u>
	Represented By:		
	Co-operative Bank		32,221
	PayPal		<u>2,696</u>
			<u>34,917</u>

Chair's Annual Report 2022-23

The charity's activity was still suffering from the effects of the COVID-19 pandemic in this financial year, so unfortunately our fundraising efforts were limited. We have still had a busy year and a summary of our activities is below:

- A patient support group was held at Addenbrooke's Hospital, Cambridge, which was very well attended. Professor Eamonn Maher and members of his team gave a talk on their current research projects. This was the first opportunity that patients and carers had had to meet up since the COVID-19 pandemic and I believe it that everyone gained some benefit from being able to see people "face-to-face".
- We were able to make payment of the ring-fenced £20,000 which was awarded to the Francis Crick Institute (see (3) below). A group of trustees visited the Institute in October 2022 and were given a tour of the laboratories, plus a talk about the work they are doing with VHL genetic mutations at molecular level.
- There are currently three projects in progress which are being funded by our Grant Awards
 - (1) £60,000 VHL patient registry and surveillance project - Genetic Centre at Addenbrooke's, Cambridge under the stewardship of Professor Eamonn Maher.
 - (2) £60,000 VHL gene analysis of the 100,000 genome project data - Genetic Centre at Addenbrooke's, Cambridge under the stewardship of Professor Eamonn Maher.
 - (3) £20,000 Saturation Genome Editing to Define Genotype/Phenotype Relationships in VHL Disease - specific VHL research work of Professor William Drake at St Bartholomew's Hospital.
- We are expecting to make an additional Grant Award to the Francis Crick Institute in the financial year 2023-24.
- The dedicated task team formed last year were contacted by MSD (Merck) on 14th April 2022 and we have had many meetings with their representatives and the National Institute for Health and Care Excellence (NICE) to try to gain approval for the drug belzutifan (Welireg) to be funded by NHS England. The MHRA approval for this drug includes its use for RCC Clear-Cell kidney cancer, hemangioblastomas of the central nervous system and pancreatic neuro-endocrine tumours. The charity is registered as a stakeholder with NICE and will be involved in the approval process as a patient expert.
- The NICE appraisal for belzutifan (Welireg) only covers patients in England. The charity will also work with the Scottish Medicines Consortium to hopefully gain approval for patients based in Scotland. It is understood that Wales and Northern Ireland usually follow England's lead. Ireland's patients will be included in the EU process.
- Belzutifan is already approved in the US and many VHL patients report excellent results reducing the need for surgical treatments.
- A number of our UK members have had or are in the process of having life-changing surgeries as a treatment for VHL tumours and belzutifan, if it had been available, might have provided an alternative. We hope to obtain belzutifan approval and in the meantime, we wish everyone good recoveries.

Graham Lovitt
Chair

**Report to the Trustees of the
VHL UK/Ireland Charity
Accounts for the Year Ended 5 April 2023**

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the Charities Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that, in any material respect, the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Paul David Griffiths FCA
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Date: 2/2/2024