

VHL UK/IRELAND

England & Wales · Charity number 1160381

Details

Status Registered

Legal form Other

Registered 2015-02-09

Register [View on the Charity Commission register](#)

Contact

Address 47 Tiln Lane
Retford
DN22 6SN

Phone 07762525561

Email uk@vhl-uk-ireland.org

Website <http://vhl-uk-ireland.org/>

Activities

Objects: TO RELIEVE THE CHARITABLE NEEDS OF PERSONS WHO HAVE VON HIPPEL-LINDAU SYNDROME (VHL) AND SIMILAR GENETIC CONDITIONS SUCH AS HEREDITARY LEIOMYOMATOSIS AND RENAL CELL CANCER (HLRCC) AND BIRT-HOGG-DUBE SYNDROME (BHD) AND THEIR FAMILIES AND CARERS IN THE UK AND IRELAND FOR THE PUBLIC BENEFIT IN PARTICULAR BUT NOT EXCLUSIVELY BY 1) PROVIDING SUPPORT AND ADVICE REGARDING THEIR GENETIC CONDITIONS, 2) PROVIDING FUNDS FOR RESEARCH INTO THE GENETIC CONDITIONS AND FOR EQUIPMENT TO ASSIST WITH SUCH RESEARCH, 3) TO ADVANCE THE EDUCATION OF THE PUBLIC IN ALL MATTERS CONCERNING THE GENETIC CONDITIONS.

Activities: The main activity of the charity is raising funds through donations and fund-raising activities in order to fund specialised research into the conditions of VHL, BHD and HLRCC at centres of excellence in the UK and Ireland. The charity also provides personal support through telephone and social media to patients and carers with the above conditions and maintains a web-site.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

Geography

- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£20,076	£38,915	-	-
2024-04-05	£38,000	£1,900	-	-
2023-04-05	£8,110	£21,514	-	-
2022-04-05	£18,131	£801	-	-
2021-04-05	£34,824	£60,619	-	-

Trustees

Name	Role	Appointed
Mark Ashley Lodge	Chair	2026-01-29
Charli Christina Diane Lawton		2026-05-01
Dr Antony Richard Horton Ph D		2015-05-07
Francesca Goddard		2020-06-11
GRAHAM JOHN LOVITT		2013-03-01
JANICE HEPWORTH		2015-05-07
John Allan Hepworth		2016-05-22
Joyce Noreen Bonin		2026-05-26
Kathryn Chapman		2020-06-11
Kim Lara Vaughan		2020-06-11
Nancy Molyneaux-Finley		2024-03-11
ROXANNE MICA DAPHNE BONIN BA HONS		2014-11-11
Tantara Fox-Stillwell		2020-06-11

VHL UK/IRELAND

England & Wales - Charity number 1160381

Accounts



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 2024



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

Receipts and Payments Account (UK) for the Year Ended 5 April 2024

05 April 2023			05 April 2024	
£			£	£
	Receipts:			
7,909	Donations (Inc. Gift Aid)			31,163
-	Fundraising Activities			6,207
201	Trading Activities			630
<u>8,110</u>				<u>38,000</u>
	Payments:			
20,086	Grants and Donations	821		
787	Patient Support	391		
194	Subscriptions	94		
445	Website and Postage	489		
2	Fundraising Charges	105		1,900
<u>21,514</u>				
- 13,404	Net Receipts/-Payments			<u>36,100</u>
48,321	Opening Balance			34,917
- 13,404	Net Receipts/-Payments			36,100
<u>34,917</u>	Closing Balance			<u>71,017</u>
	Represented By:			
	Co-operative Bank			70,017
	PayPal			1,000
				<u>71,017</u>



Chair's Annual Report 2023-24

The charity has recovered well from the effects of COVID-19 this year and our donations and fundraising total was a magnificent £37,370. Events included:

- A Charity Ball, in conjunction with Cancer-52, which was incredibly well supported and raised in excess of £6,000 for each of the two charities – our most successful ball yet;
- Events organised by patients and their families, including a Golf Day, sponsored walks, and a sponsored abseil from Wakefield Cathedral!
- VHL Awareness Month in May was very successful this year, raising awareness and funds for the charity with quizzes, cake sales, fashion sales and ad-hoc donations.

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.
- A further £35,000 grant award is currently ring-fenced for a research project at the Crick Institute which we are expecting to release in 2024-25.

The charity continued to work with MSD (Merck) and the National Institute for Health and Care Excellence (NICE) in respect of the approval of NHS funding for the new drug belzutifan (Welireg). 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 continues to be involved in the approval process as a patient expert.

The charity was also involved with the Scottish Medicines Consortium in its appraisal of belzutifan (Welireg) and we were delighted when NHS funding was approved for Scotland in October 2023. Scotland was the first country in Europe to provide funding for NHS patients and this was a huge milestone for the VHL community. It is understood that Wales and Northern Ireland usually follow England's lead. Ireland's patients will be included in the EU process.

Graham Lovitt
Chair

**Report to the Trustees of the
VHL UK/Ireland Charity
Accounts for the Year Ended 5 April 2024**

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.

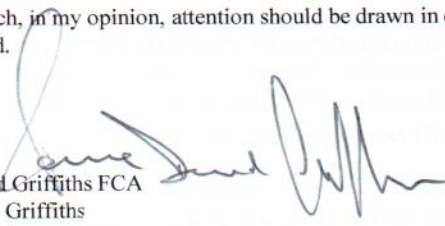
Independent examiner's statement

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
Hepworth Griffiths
Chartered Accountants
47 Grove Street
Retford
Nottinghamshire
DN22 6LA

Date:

3/2/2025

VHL UK/IRELAND

England & Wales - Charity number 1160381

Accounts



ANNUAL ACCOUNTS
ANNUAL CHARITY REPORT
&
INDEPENDENT EXAMINER'S REPORT

Year Ended 5 April 2021



Receipts and Payments Account (UK) for the Year Ended 5 April 2021

05 April 2020		05 April 2021	
		£	£
Receipts:			
25,330	Donations		34,442
4,604	Trading Activities		382
<u>29,934</u>			<u>34,824</u>
Payments:			
40,000	Grants and Donations	60,000	
534	Patient Support	-	
252	Subscriptions	72	
515	Telephone, Internet and Postage	260	
142	Fundraising Charges	287	60,619
<u>41,443</u>			
<u>-</u>	Net Payments	<u>-</u>	<u>25,795</u>
68,295	Opening Balance		56,786
<u>-</u>	Net Payments	<u>-</u>	<u>25,795</u>
<u><u>56,786</u></u>	Closing Balance		<u><u>30,991</u></u>



Chair's Annual Report 2020-2021

The charity has like many other charities had to adapt to the restrictions imposed to deal with the COVID-19 pandemic. All individual fund-raising events at locations were curtailed and there were relatively few on-line replacements. With fewer fund-raising events the demand for some on-line shop merchandise also decreased. Despite this there was one significant fundraiser organised by Charles White raising ~£20K and just recently a legacy donation of £10K (to appear in the next year's account reporting).

There were significant problems with the charity's website which had allowed external information to be uploaded without the necessary controls. This combined with the web designer leaving the charity meant that it became a target for spammers and hackers. The decision was taken to rewrite the whole website using a professional website designer. He was able to restore all the significant historical information and now has a small annual maintenance contract so there should be no repeat of the previous problems.

The charity continues to support hosting of the websites for both the charity www.vhl-uk-ireland.org and the HLRCC Family Alliance www.hlrccinfo.org. The latter was upgraded to use SSL which improves its security. Note that the HLRCCFA is a project of the VHL Alliance.

The charity continues to provide a limited patient support service by telephone.

The charity increased by £20,000 each the two previous grant awards of £40,000 each to the Genetic Centre at Addenbrooke's, Cambridge under the stewardship of Professor Eamonn Maher. These increases enable the work of these projects to continue.

These projects are:

- (1) a VHL patient registry and surveillance project; and
- (2) a VHL gene analysis of the 100,000 genome project data.

The fundraiser by Charles White enabled the charity to make a grant award of £20K to be made to the Crick's Institute to support the specific VHL research work of Professor William Drake at St Bartholomew's Hospital. The project is Saturation Genome Editing to Define Genotype/Phenotype Relationships in VHL Disease.

It is hoped that with the lifting of COVID-19 restrictions the charity will be able to expand its fundraising activities back to its previous levels.

VHL UK/Ireland Charity is registered in England and Wales (1160381)
and Ireland (20101039)

**Report to the Trustees of the
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Accounts for the Year Ended 5 April 2021**

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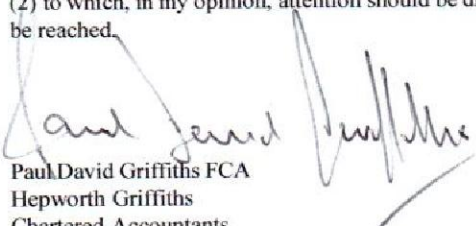
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Date:

24 November 2021