

HAEMOPHILIA WALES

England & Wales - Charity number 1158941

Details

Status Registered

Legal form CIO

Registered 2014-10-23

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

Contact

Address 17 Alfreda Road
Whitchurch
Cardiff
CF14 2EH

Phone 07979 527599

Email info@haemophiliawales.org

Website www.haemophiliawales.org

Activities

Objects: THE OBJECT OF THE CIO IS TO RELIEVE PEOPLE WITH HAEMOPHILIA, VON WILLEBRANDS DISEASE AND OTHER BLEEDING DISORDERS, THEIR FAMILIES, CARERS AND BEREAVED FAMILIES WHO ARE IN NEED PARTICULARLY BY THE PROVISION OF INFORMATION, ADVOCACY AND SUPPORT.

Activities: Haemophilia Wales provided information, support and advocacy to everyone affected by Inherited Bleeding Disorders. We have representation on the All Wales Advisory Group and the Cross Party Group on Haemophilia and Contaminated Blood. We organise events for families to network and gain mutual support, we campaign on behalf of Haemophiliacs with contaminated blood.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Throughout Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-10-31	£6,893	£5,036	-	-
2023-10-31	£3,009	£5,941	-	-
2022-10-31	£1,433	£1,674	-	-
2021-10-31	£730	£2,674	-	-
2020-10-31	£927	£2,677	-	-

Trustees

Name	Role	Appointed
CRAIG SUGAR		2013-11-01
DAVID THOMAS BA HONS		2013-11-01
Michael O'Driscoll Mr		2019-11-01
NICHOLAS PATRICK KELLY		2013-11-01
NICK MORAN		2013-11-01
Nigel Miller		2018-07-27
PATRICIA GAYNOR SUMMERS		2013-11-01
TONY SUMMERS		2013-11-01

HAEMOPHILIA WALES

England & Wales - Charity number 1158941

Accounts

Haemophilia Wales Trustees Annual Report : November 1st 2023 -31st October 2024

Throughout the year Haemophilia Wales continued to provide information and support to patients and families with Haemophilia and Inherited Bleeding Disorders of all ages, across Wales. We also provide advocacy and assistance to individuals and bereaved families impacted by Infected Blood via blood transfusion.

We actively engage with the Haemophilia Centres throughout Wales to ensure they are providing the care and support needed by patients and families. We keep in regular contact with members to help identify any gaps in the service and to ensure concerns are raised with staff, local Health Boards and NHS Commissioners.

We have regular meetings with North Wales patients and staff at the North Wales Operational and Strategic Group meetings and Expert Patient Forum meetings.

We organised and funded World Haemophilia Day, the children's summer event at Folly Farm and the Children's Christmas Party. In addition to this we provide networking opportunities to families both in person and via social media. We also meet with parents and families as required.

We provide Hardship Grants to those in urgent need of financial assistance.

Haemophilia Wales, patients and families meet regularly with the Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly. The Group is Chaired by Rhun Iwan Iwan MS and the meetings are always well supported by patients, families and members of the Senedd. The meetings provide a platform for patients to raise any concerns they may have about service provision in Wales and the Infected Blood Inquiry. This forum provides a vital voice to patients who are currently receiving treatment in Wales and to bereaved families continuing to fight for justice for infected blood.

Haemophilia Wales is a Core Participant status at the Infected Blood Inquiry and our lawyers at Watkins and Gunn are recognised legal representatives at the Inquiry. We hold regular update meetings in North and South Wales for our members.

The Infected Blood Final Report and Recommendations were published on 20th May 2024 which reported a catalogue of failures at systemic, collective and individuals levels with more than 3,000 deaths attributable to Infected Blood.

We will continue to work tirelessly to ensure that the Infected Blood Inquiry's recommendations are implemented by the Government.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Howe Street, Woking

1150345

Receipts and payments accounts

CC16a

For the period from **01/11/2023** To **31/10/2024**

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	-	-	-	6,885	3,000
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	-	-	-	6,885	3,000
A2 Asset and investment sales, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	-	-	-	6,885	3,000
A3 Payments					
Administration	-	-	-	1,090	295
Meetings and Events	-	-	-	5,791	5,741
Marketing Grants	-	-	-	280	180
Travel expenses	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	6,636	5,941
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	6,636	-
Total payments	-	-	-	6,636	5,941
receipts/(payments)	-	-	-	1,930	1,976
A5 Transfers between	-	-	-	-	-
A5 Cash funds last year	-	-	-	-	-
Cash funds this year end	-	-	-	1,930	2,906

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		to the nearest £	to the nearest £	to the nearest £
B1 Cash funds		-	-	-
		-	-	-

	-	-	-
Total cash funds	-	-	-

(Open balances with receipts and payments accounts)

	Unrestricted funds in receipt of	Restricted funds in receipt of	Endowment funds in receipt of
B2 Other monetary assets	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets		-	-
		-	-
		-	-
		-	-

	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use		-	-
		-	-
		-	-
		-	-
		-	-
		-	-

	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities		-	
		-	
		-	
		-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
<i>dunley</i>	STANIS KOLY	26/7/25

HAEMOPHILIA WALES

England & Wales - Charity number 1158941

Accounts

Haemophilia Wales Trustees Annual Report : November 1st 2022 -31st October 2023

Haemophilia Wales continues to provide information and support to patients and families with Haemophilia and Inherited Bleeding Disorders of all ages, across Wales.

In addition to this will provide assistance to individuals and bereaved families involved in the Infected Blood Inquiry.

We actively engage with the Haemophilia Centres throughout Wales to ensure they are providing the care and support needed by patients and families. We keep in regular contact with members to help identify any gaps in the service and to ensure concerns are raised with staff, local Health Boards and NHS Commissioners.

We have regular meetings with North Wales patients and staff at the North Wales Operational and Strategic Group meetings and Expert Patient Forum meetings.

We have organised and funded Children's Christmas Parties and networking events for the newly diagnosed families in 2022 and 2023. In addition to this we meet with parents and families as required.

We meet regularly as a group to provide updates on the Infected blood Inquiry.

Hardship Grants are provided from donations to those in urgent need of financial assistance.

We keep in close contact with Members of the Senedd and MPs to ensure our voices are heard at the Welsh Assembly and Westminster. We assist families to contact and meet with their MPs and Members of the Welsh Parliament when required.

Cross Party Group meetings on Haemophilia and Contaminated Blood at the Welsh Assembly continue to be held at the Welsh Assembly. The Group is Chaired by Rhun Iddon MS and the meetings are always well supported by patients, families and members of the Senedd. The meetings provide a platform for patients to raise any concerns they may have about service provision in Wales and the Infected Blood Inquiry. This forum provides a vital voice to patients who are currently receiving treatment in Wales and to bereaved families continuing to fight for justice for infected blood.

Haemophilia Wales has Core Participant status at the Infected Blood Inquiry and our lawyers at Watkins and Gunn are recognised legal representatives at the Inquiry. We held regular meetings throughout the year in preparation for our legal submission to the Infected Blood Inquiry recommendations. The Inquiry is ongoing and Sir Brian Langstaff announced Interim compensation payments to for previously unrecognised deaths

In April 2023 but at this time the Government have not implemented this recommendation.

The Inquiry's Final Recommendations are expected in May 2024.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Haemophilia Wales

1158941

Receipts and payments accounts

CC16a

For the period from	Period start date 01/11/2022	To	Period end date 31/10/2023
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations	-	-	-	3,009	1,443
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	-	-	-	3,009	1,443
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	-	-	-	3,009	1,443
A3 Payments					
Administration	-	-	-	200	267
Childrens Activities	-	-	-	-	-
Christmas Parties	-	-	-	1,741	-
Folly Farm	-	-	-	3,250	-
Hardship Grants	-	-	-	750	750
Travel expenses	-	-	-	-	441
Funeral Donations	-	-	-	-	216
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	5,941	1,674
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	-	-	-	5,941	1,674
Net of receipts/(payments)	-	-	-	5,941	1,674
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	-	-	-	53	2,985

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		-	-	-
		-	-	-
		-	-	-
	Total cash funds	-	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval

HAEMOPHILIA WALES

England & Wales - Charity number 1158941

Accounts

Haemophilia Wales Trustees Annual Report :

November 1st 2021-31st October 2022

Haemophilia Wales continues to provide information and support to patients and families in Wales. We keep in regular contact with members to ensure any new developments and issues are raised with staff and local Health Boards. We have regular meetings with North Wales patients and staff at the North Wales Operational and Strategic Group meetings and Expert Patient Forum meetings.

We keep in close contact with Members of the Senedd and MPs to ensure our voices are heard at the Welsh Assembly and Westminster.

Our meetings with the Cross Party Group on Haemophilia and Contaminated Blood Chaired by Rhun Iwan Iwan MS are well supported by patients, families and members of the Senedd. The meetings provide a platform for patients to raise any concerns they may have about service provision in Wales and the Infected Blood Inquiry. This forum provides a vital voice to patients who are currently receiving treatment in Wales and to bereaved families continuing to fight for justice for infected blood.

Haemophilia Wales has Core Participant status at the Infected Blood Inquiry and our lawyers at Watkins and Gunn are recognised legal representatives at the Inquiry. We have regular meetings throughout the year in preparation for our legal submission to the Infected Blood Inquiry recommendations.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name _____ No (if any) _____

Receipts and payments accounts

CC16a

For the period from 01/11/2021 To 31/10/2022

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Voluntary Income	-	-	-	-	-
Grants	-	-	-	-	-
Donations	-	-	-	1,433	730
Interest	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	-	-	-	1,433	730
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	-	-	-	1,433	730
A3 Payments					
Administration	-	-	-	267	565
Gifts to Haemophilia Centre website	-	-	-	-	1,969
Hardship Grants	-	-	-	750	-
Travel expenses	-	-	-	441	-
Funeral donations	-	-	-	216	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,674	-	-	1,674	2,674
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,674	-	-	1,674	2,674
Net of receipts/(payments)	- 1,674	-	-	1,674	- 1,944
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	- 1,674	-	-	2,985	3,226

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		-	-	-
		-	-	-
		-	-	-
	Total cash funds	-	-	-
	(agree balances with receipts and payments account(s))	Agreement Error	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		Date of approval

HAEMOPHILIA WALES

England & Wales - Charity number 1158941

Accounts



Charity No 1158941	CC16a
Haemophilia Wales	

Receipts and payments accounts

For the period from	01/11/2020		
For the period to	31/10/2021		

Section A Receipts and payments

Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £

A1 Receipts

Voluntary Income	-	-	-	-
Grants		-	-	
Donations	730	-	730	
Interest		-	-	
		-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
Sub total (Gross income for AR)	730		730	927

investment sales, (see				
	-	-	-	-
	-	-	-	-
Sub total	-	-	-	-

Total receipts	730	-	-	730	927
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A3 Payments

		-	-	-
Activity days		-	-	-
Hardship funds		-	-	-
Administration	565	-	-	565
Gifts to Haemophilia Centre website	1,959	-	-	1,959
	160	-	-	160
		-	-	-
		-	-	-
	-	-	-	-

Sub total	2,674	-	-	2,674	2,677
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A4 Asset and investment purchases, (see table)

	-	-	-	-	
	-	-	-	-	
Sub total	2,674	-	-	2,674	-

Total payments	2,674	-	-	2,674	2,677
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Net of receipts/(payments)	1,944	-	-	1,944	1,750
A5 Transfers between funds		-	-		-
A6 Cash funds last year end	5,170	-	-	5,170	6,920
Cash funds this year end	3,226	-	-	3,226	5,170

HAEMOPHILIA WALES

England & Wales - Charity number 1158941

Accounts

Haemophilia Wales Trustees Annual Report :

November 1st 2019-31st October 2020

We continue to provide information and support to Haemophilia and transfusion patients and families across Wales.

Haemophilia Wales attended the Infected Blood Inquiry Hearings in London and participated in the Inquiry Engagement meetings in North and South Wales.

The Cross Party Group at the Welsh Assembly met 3 times and patients and families were given updates on the progress of the Inquiry and service provision in Haemophilia care across Wales.

Much of our work has focused on strengthening the North Wales Haemophilia service and patients and staff meetings continue to ensure that these improvements are implemented.

Caroline Coffey Clinical Psychologist and Julie Armytage were appointed to provide Psychological support at the Wales Infected Blood Support Scheme. As a result of continued engagement with Haemophilia Centres across Wales 2 Haemophilia Consultants and 2 Haemophilia nurses were appointed.

Haemophilia Wales attended a meeting at the Cabinet Office to discuss levelling Infected Blood Support payments across the UK as requested by Sir Brian Langstaff Chair of the Infected Blood Inquiry.



**CHARITY COMMISSION
FOR ENGLAND AND WALES**

Charity No 1158941	CC16a
Haemophillia Wales	

Receipts and payments accounts

For the period from	01/11/2019		
For the period to	31/10/2020		

Section A Receipts and payments

Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £

A1 Receipts

Voluntary Income	-	-	-	-
Grants		-	-	
Donations	898	-	-	898
Interest	29	-	-	29
		-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
Sub total (Gross income for AR)	927			927

investment sales, (see				
	-	-	-	-
	-	-	-	-
Sub total	-	-	-	-

Total receipts	927	-	-	927	3,981
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A3 Payments

		-	-		-
Activity days	93	-	-	93	
Hardship funds	470	-	-	470	
Administration	2,114	-	-	2,114	
		-	-		-
		-	-		-
		-	-		-
		-	-		-
	-	-	-		-
Sub total	2,677	-	-	2,677	5,777

A4 Asset and investment purchases, (see table)

	-	-	-	-	
	-	-	-	-	
Sub total	2,677	-	-	2,677	-

Total payments	2,677	-	-	2,677	5,777
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Net of receipts/(payments)	1,750	-	-	1,750	1,796
A5 Transfers between funds		-	-		-
A6 Cash funds last year end	6,920	-	-	6,920	7,923
Cash funds this year end	5,170	-	-	5,170	6,127