

APPENDIX 1



Office of the Scottish Charity Regulator

Trustees' Annual Report for the period							
Period start date				Period end date			
From	Day	Month	Year	To	Day	Month	Year
	01	04	2017		31	03	2018

Reference and administration details

Charity name	Haemophilia Scotland
Other names charity is known by	
Registered charity number	SC044298
Charity's principal address	SCVO Charity Business Hub, 4 th Floor, Hayweight House, 23 Lauriston Street Edinburgh Scotland, UK
	Postcode EH3 9DQ

Names of the charity trustees on date of approval of Trustees' Annual Report

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Bill Wright	Chair		
2	Lynne Black	Vice Chair		
3	James Geekie	Treasurer	Co-opted 18 August 2018	
4	Carolyn McGimpsey	Secretary		
5	Nikki Gandy			
6	Hugh MacInnes			
7	Nancy Brodie		Elected 20 May 2017	
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Reference and administration details

Names of all other charity trustees during the period, if any, (for example, those who resigned part way through the financial period)

Name	Dates acted if not for whole year
Lynn Fraser	Resigned 1 August 2018
Dan Hewins	Resigned 19 th May 2018
Heather MacLeod	Resigned 19 th May 2018

Structure, governance and management

Type of governing document

Haemophilia Scotland converted to a SCIO (Scottish Charitable Incorporated Organisation) on 14 May 2015. Prior to this it was an unincorporated organisation with a constitution dated 3 October 2014. The SCIO constitution was amended on 17 July 2016.

Trustee recruitment and appointment

The Constitution of Haemophilia Scotland provides for up to 12 trustees who must be a member of the organisation in order to be eligible. Trustees are elected at the Annual General Meeting or by co-option by those elected following the Annual General Meeting. One third of the Trustees retire at each AGM (the third is comprised of the longest in office since last elected/re-elected).

Objectives and activities

Charitable purposes

- (a) To further as a primary objective the health, education, wellbeing, and the social and economic welfare of all those in Scotland with a bleeding disorder and their families.
- (b) To further the health, education, and the social and economic welfare of the haemophilia and bleeding disorders community in Scotland and internationally. And in furtherance thereof:
 - (i) To bring together individuals and organisations that share such interests.
 - (ii) Where possible, to cultivate reciprocal relations with organisations that have similar aims, relevant health, social welfare and educational objectives or which may otherwise support or benefit the SCIO.

Summary of the main activities in relation to these objects

Haemophilia Scotland meets its charitable purposes by providing;

- a) Direct support and opportunities for members of the Scottish bleeding disorders community to support each other through events and mentoring.
- b) Independent and patient friendly information relevant to living with a bleeding disorder.
- c) Advocacy services to represent people with bleeding disorders and work closely with the Scottish Haemophilia Centres and other key stakeholders to secure the best possible treatment and care.

Achievements and performance

Summary of the main achievements of the charity during the financial period

Haemophilia Scotland's five year strategy divides our activities into three themes; support, information, and advocacy. During the 2017/18 financial year the charity made significant progress in all three.

Support

As part of our Annual General Meeting (AGM) we provided a trip on Loch Katrine for all ages to meet and make connections. Our children and families came together for a shark party at Deep Sea World in North Queensferry. They also visited Hampden Park to strengthen our community and this provided opportunities for mutual support. Our go-karting event for teenagers helped prepare for our summer sailing challenge. The Haemophilia Scotland Women's Group launched an international quilting project to bring women with bleeding disorder together from across Scotland and put them in touch with affected women from around the world. With the Glasgow Haemophilia Centre we collected toiletries for women with bleeding disorders from developing countries. There were women's support events in Glasgow and St Andrews. We concluded our successful Malawi Diagnosis Project and conducted an assessment visit to the Kenya Haemophilia Association to evaluate the potential for an organisational twinning.

Information

We provide regular news through the blog on our website while continuing to expand our information provision. Specifically, new information was added about the sporadic Creutzfeldt-Jakob Disease (sCJD) cases in the UK inherited bleeding disorders community. We provided information on changes in staff at Centres, how to respond to the severe weather, updated on the development of gene therapy, and on the NHS GGC response to the bacterial infections at the Glasgow Royal Hospital for Children. We also promoted two events run by Scottish Haemophilia Centres.

Advocacy

We held a reception at the Scottish Parliament to highlight the findings of our needs assessment conducted in partnership with the Scottish Inherited Bleeding Disorders Network (SIBDN). We engaged with the SIBDN to work in partnership with everyone involved in treatment and care in Scotland to continuously improve haemophilia services. We publicly wrote to the CEO of NHS GGC about the proposal to relocate the GRI Haemophilia Unit.

We held joint campaign meetings with the Scottish Infected Blood Forum (SIBF) so that those in Scotland affected by contaminated blood and blood products infections are well informed and campaign with a united voice. We supported the launch of the Scottish Infected Blood Support scheme with information for members and a press release focused in encouraging registrations. We responded to the UK Government's announcement that there would be a UK Contaminated Blood and Blood Products Public Inquiry by publishing a joint, Scottish, position statement to clarify the views of affected people in Scotland about the priorities for the new Inquiry and how it should learn from the experience of the Penrose Inquiry. In this context we also participated in an all-campaigners meeting with the former Bishop of Liverpool, James Jones, seeking to agree a combined approach to the UK Public Inquiry. We gave evidence to the All Party Parliamentary Group on Haemophilia about the patient experience of the Scottish Infected Blood Support Scheme, the Penrose Inquiry, and position on how the UK Inquiry should be established. We participated in a meeting with the de facto Deputy Prime Minister about the Infected Blood Inquiry.

APPENDIX 1

Summary of the main achievements of the charity during the financial period (continued)

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Financial review

Brief statement of the charity's policy on reserves

It is our policy to maintain reserves equivalent to a minimum of three months running cost.

Details of any deficit

Haemophilia Scotland does not have a deficit.

Donated facilities and services (if any)

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Other optional information

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)

William Wright

Full name(s)

WILLIAM WRIGHT

Position (e.g. Chair)

CHAIR

Date

27/06/19

OSCR Office of the Scottish Charity Regulator	Enter charity name below						Enter SC No. below	
	HAEMOPHILIA SCOTLAND						SC044298	
Receipts and payments accounts								
For the period from	Period start date			to	Period end date			
	Day	Month	Year		Day	Month	Year	
	01	April	2017		31	March	2018	
Section A Statement of receipts and payments								
	Unrestricted funds	Restricted funds	Expendable endowment funds	Permanent endowment funds	Total funds current period	Total funds last period		
	to nearest £	to nearest £	to nearest £	to nearest £	to nearest £	to nearest £		
A1 Receipts								
Donations	1,600	11,200			12,800	74,066		
Legacies					-	-		
Grants	100,000	8,875			108,875	37,786		
Receipts from fundraising activities	7,172	7,452			14,624	-		
Gross trading receipts					-	-		
Income from investments other than land and buildings	6				6	21		
Rents from land & buildings					-	-		
Gross receipts from other charitable activities					-	-		
					-	-		
A1 Sub total	108,778	27,527	-	-	136,305	111,873		
A2 Receipts from asset & investment sales								
Proceeds from sale of fixed assets					-	-		
Proceeds from sale of investments					-	-		
A2 Sub total	-	-	-	-	-	-		
Total receipts	108,778	27,527	-	-	136,305	111,873		
A3 Payments								
Expenses for fundraising activities	1,066				1,066	-		
Gross trading payments					-	-		
Investment management costs					-	-		
Payments relating directly to charitable activities	89,781	21,146			110,927	122,876		
Grants and donations					-	-		
Governance costs:					-	-		
Audit / independent examination	900				900	1,680		
Preparation of annual accounts	1,000				1,000	1,000		
Legal costs					-	1,080		
AGM/Conference	4,384				4,384	3,182		
					-	-		
A3 Sub total	97,131	21,146	-	-	118,277	129,818		
A4 Payments relating to asset and investment movements								
Purchases of fixed assets					-	-		
Purchase of investments					-	-		
A4 Sub total	-	-	-	-	-	-		
Total payments	97,131	21,146	-	-	118,277	129,818		
Net receipts / (payments)	11,647	6,381	-	-	18,028	(17,945)		
A5 Transfers to / (from) funds	(2,156)	2,156			-	-		
Surplus / (deficit) for year	9,491	8,537	-	-	18,028	(17,945)		

Section B Statement of balances

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Expendable endowment funds to nearest £	Permanent endowment funds to nearest £	Total current period to nearest £	Total last period to nearest £
B1 Cash funds	Cash and bank balances at start of year	42,936	38,447			81,382	99,327
	Surplus / (deficit) shown on receipts and payments account	9,491	8,537			18,028	(17,945)
						-	
	Cash and bank balances at end of year	52,426	46,984	-	-	99,410	81,382

(Agree balances with receipts and payments account(s))

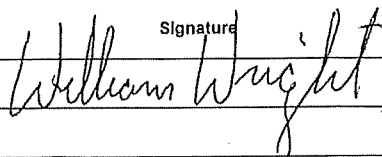
Categories	Details	Fund to which asset belongs	Market valuation to nearest £	Last year to nearest £
B2 Investments				
		Total	-	-

Categories	Details	Fund to which asset belongs	Cost (if available) to nearest £	Current value (if available) to nearest £	Last year to nearest £
B3 Other assets					
			Total	-	-

Categories	Details	Fund to which liability relates	Amount due to nearest £	Last year to nearest £
B4 Liabilities				
		Total	-	-

Categories	Details	Fund to which liability relates	Amount due (estimate) to nearest £	Last year to nearest £
B5 Contingent liabilities				
		Total	-	-

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

Signature	Print Name	Date of approval
	WILLIAM WRIGHT	01/07/19

Section C Notes to the Accounts

C1 Nature and purpose of funds (may be stated on analysis of funds worksheets)

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C2 Grants

Type of activity or project supported	Individual / institution	Number of grants made	£
Total			-

C3a Trustee remuneration

If no remuneration was paid during the period to any charity trustee or person connected to a trustee cross this box (otherwise complete section 3b)	x
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C3b Trustee remuneration - details

Authority under which paid	£

C4a Trustee expenses

If no expenses were paid to any charity trustee during the period then cross this box (otherwise complete section 4b)	
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C4b Trustee expenses - details

	Number of trustees	£
Travel & subsistence	4	4,967

C5 Transactions with trustees and connected persons

Nature of relationship	Nature of transaction	Transaction amount (£)	Balance outstanding at period end (£)

C6 Other information

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HAEMOPHILIA SCOTLAND

SC044298

Additional analysis (1)

Analysis of receipts and payments

1 Donations

	Unrestricted funds to nearest £	Restricted funds to nearest £	Expendable endowment funds to nearest £	Permanent endowment funds to nearest £	Total current period to nearest £	Total last period to nearest £
Pfizer	600				600	12,000
Behring		3,500			3,500	-
Trust	1,000				1,000	19,066
Bayer		500			500	15,000
NHS		1,000			1,000	-
Swedish Orph		6,200			6,200	28,000
Total	1,600	11,200	-	-	12,800	74,066

2 Grants

	Unrestricted funds to nearest £	Restricted funds to nearest £	Total current period to nearest £	Total last period to nearest £
Scottish Government	100,000	6,500	106,500	-
Alliance Scotland - Self Management			-	14,702
Lloyds TSB Foundation			-	19,875
World Federation of Haemophilia		2,375	2,375	3,209
Total	100,000	8,875	108,875	37,786

3 Gross receipts from other charitable activities

	Unrestricted funds to nearest £	Restricted funds to nearest £	Expendable endowment funds to nearest £	Permanent endowment funds to nearest £	Total current period to nearest £	Total last period to nearest £
Other	7,172	7,452			14,624	-
					-	-
					-	-
					-	-
					-	-
					-	-
Total	7,172	7,452	-	-	14,624	-

4 Payments relating directly to charitable activities

	Unrestricted funds to nearest £	Restricted funds to nearest £	Expendable endowment funds to nearest £	Permanent endowment funds to nearest £	Total current period to nearest £	Total last period to nearest £
Travel & Subsistence	9,962				9,962	5,395
Establishment Costs	12,537				12,537	10,184
Office Expenses	488				488	370
Printing, Postages and Stationary	824				824	1,637
Subscriptions	1,020				1,020	485
Project costs	4,855	21,146			26,001	44,402
Staff Costs	55,057				55,057	55,820
Marketing Costs	1,617				1,617	4,322
Bank charges	411				411	261
World Congress	3,010				3,010	-
					-	-
Total	89,781	21,146	-	-	110,927	122,876

Additional analysis (2)

5 Breakdown of unrestricted funds

	Unrestricted fund 1 - enter name of fund below	Unrestricted fund 2 - enter name of fund below	Unrestricted fund 3 - enter name of fund below	Unrestricted fund 4 - enter name of fund below	Total unrestricted funds	Total unrestricted funds last period
Receipts						
Donations	1,600				1,600	39,671
Legacies					-	-
Grants	100,000				100,000	14,702
Receipts from fundraising activities	7,172				7,172	-
Gross trading receipts					-	-
Income from investments other than land and buildings	6				6	21
Rents from land & buildings					-	-
Gross receipts from other charitable activities					-	-
Sub total	108,778	-	-	-	108,778	54,394
Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	-
Proceeds from sale of investments					-	-
Sub total	-	-	-	-	-	-
Total receipts	108,778	-	-	-	108,778	54,394
Payments						
Expenses for fundraising activities	1,066				1,066	950
Gross trading payments					-	-
Investment management costs					-	-
Payments relating directly to charitable activities	89,781				89,781	102,894
Grants and donations					-	-
Governance costs:						
Audit / independent examination	900				900	1,680
Preparation of annual accounts	1,000				1,000	1,000
Legal costs					-	1,080
AGM & Conference	4,384				4,384	3,182
					-	-
Sub total	97,131	-	-	-	97,131	110,786
Payments relating to asset and investment movements						
Purchases of fixed assets					-	-
Purchase of investments					-	-
Sub total	-	-	-	-	-	-
Total payments	97,131	-	-	-	97,131	110,786
Net receipts / (payments)	11,647	-	-	-	11,647	(56,392)
Transfers to / (from) funds	(2,156)				(2,156)	
Surplus / (deficit) for year	9,491	-	-	-	9,491	(56,392)

Nature and purpose of funds

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HAEMOPHILIA SCOTLAND

SC044298

Additional analysis (3)

6 Breakdown of restricted funds

	Restricted fund 1 - enter name of fund below	Restricted fund 2 - enter name of fund below	Restricted fund 3 - enter name of fund below	Restricted fund 4 - enter name of fund below	Restricted fund 5 - enter name of fund below	Restricted fund 6 - enter name of fund below	Restricted fund 7 - enter name of fund below	Total restricted funds	Total restricted funds last period
	Malawi	Memorial Fund	Kenya	Teenagers	World Federation	Nurses	Womens Group		
Receipts									
Donations					5,200	5,000	1,000	11,200	34,395
Legacies								-	-
Grants	6,500		2,375					8,875	23,084
Receipts from fundraising activities	107	7,345						7,452	
Gross trading receipts								-	
Income from investments other than land and buildings								-	
Rents from land & buildings								-	
Gross receipts from other charitable activities								-	
Sub total	6,607	7,345	2,375	-	5,200	5,000	1,000	27,527	57,479
Receipts from asset & investment sales									
Proceeds from sale of fixed assets								-	
Proceeds from sale of investments								-	
Sub total	-	-	-	-	-	-	-	-	-
Total receipts	6,607	7,345	2,375	-	5,200	5,000	1,000	27,527	57,479
Payments									
Expenses for fundraising activities								-	
Gross trading payments								-	
Investment management costs								-	
Payments relating directly to charitable activities	4,780	30	3,469	3,718	6,262	2,523	364	21,146	19,032
Grants and donations								-	
Governance costs:								-	
Audit / Independent examination								-	
Preparation of annual accounts								-	
Legal costs								-	
Sub total	4,780	30	3,469	3,718	6,262	2,523	364	21,146	19,032
Payments relating to asset and investment movements									
Purchases of fixed assets								-	
Purchase of investments								-	
Sub total	-	-	-	-	-	-	-	-	-
Total payments	4,780	30	3,469	3,718	6,262	2,523	364	21,146	19,032
Net receipts / (payments)	1,827	7,315	(1,094)	(3,718)	(1,062)	2,477	636	6,381	38,447
Transfers to / (from) funds	-	-	1,094	-	1,062	-	-	2,156	-
Surplus / (deficit) for year	1,827	7,315	-	(3,718)	-	2,477	636	8,537	38,447

Nature and purpose of funds

Malawi. Funds were received from Lloyds TSB Foundation for Scotland for the Malawi Bleeding Disorders Project for raising awareness and training 300 clinicians.

Memorial Fund. Funds are being raised for a lasting memorial to those who have died following infection with hepatitis C or HIV following their NHS treatment with contaminated blood or blood products in Scotland.

Kenya. A grant was received from the World Federation of Haemophilia to conduct an assessment visit to Kenya for a potential ongoing partnership.

Teenagers. A donation was received from Swedish Orphan Biovitrum Ltd for the Teen Transition Project.

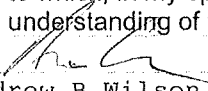
World Federation. A donation was received from Swedish Orphan Biovitrum Ltd to sponsor the Haemophilia Scotland AGM and World Federation of Haemophilia Glasgow 20-24 May 2018.

Nurses. Donations received to fund annual meetings of the Nurses and Data Managers from Scottish Haemophilia Centre.

Womens Group. The Women's Group is an informal group of Haemophilia Scotland who are encouraged to initiate projects and fundraise towards them. The group is for any woman in Scotland affected by inherited bleeding disorders.

OSCr

Office of the Scottish Charity Regulator

		Independent examiner's report on the accounts						v2
Report to the trustees/members of	Charity name	Haemophilia Scotland						
Registered charity number	SC044298							
On the accounts of the charity for the period	Period start date			to	Period end date			
	Day	Month	Year		Day	Month	Year	
	01	04	2017		31	03	2018	
Set out on pages								(remember to include the page numbers of additional sheets)
Respective responsibilities of trustees and examiner	<p>The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) 2005 Act and the Charities Accounts (Scotland) Regulations 2006. The charity trustees consider that the audit requirement of Regulation 10(1) (d) of the Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under section 44(1) (c) of the Act and to state whether particular matters have come to my attention.</p>							
Basis of independent examiner's statement	<p>My examination is carried out in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. 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 seeks 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, I do not express an audit opinion on the accounts.</p>							
Independent examiner's statement	<p>In the course of my examination, no matter has come to my attention [other than that disclosed on the attached page*]</p> <ol style="list-style-type: none"> which gives me reasonable cause to believe that in any material respect the requirements: <ul style="list-style-type: none"> to keep accounting records in accordance with section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and to prepare accounts which accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations <p>have not been met, or</p> <ol style="list-style-type: none"> to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached. 							
Signed:							Date: 28/06/2019	
Name:	Andrew B Wilson							
Relevant professional qualification(s) or body (if any):	CA							
Address:	Nelson Gilmour Smith Mercantile Chambers 53 Bothwell Street Glasgow G2 6TB							

*Please delete the words in the brackets if they do not apply. If the words do apply, set out those matters which have come to your attention on the following page.