



Trustees' Annual Report for the period

Period start date				Period end date			
From	Day	Month	Year	To	Day	Month	Year
	01	04	2016		31	03	2017

Office of the Scottish Charity Regulator

Reference and administration details

Charity name
Other names charity is known by
Registered charity number
Charity's principal address

Haemophilia Scotland
SC044298
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	Lynn Fraser	Vice Chair		
3	Lynne Black	Vice Chair		
4	Nikki Gandy	Treasurer		
5	Carolyn McGimpsey	Secretary		
6	Hugh MacInnes			
7	Dan Hewins			
8	Heather MacLeod			
9	Nancy Brodie		Elected 20 May 2017	
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

APPENDIX 1

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

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 2016/17 financial year the charity made significant progress in all three themes.

Support

Haemophilia Scotland works to provide individuals and families with inherited bleeding disorders in Scotland with direct support and opportunities to meet, share experiences, learn from one another, and offer mutual support. We did this by,

- Holding well attended Children and Families support days including a superhero trip to the Blair Drummond Safari Park and a family day out at Edinburgh Zoo.
- Launching the Diagnose Malawi Project with our partners the Society for Haemophilia and Allied Disorders (SHAD) in Malawi. Additional funds were raised from the community through our Walk RED Malawi picnic. The project trained healthcare professional in Malawi to identify potential bleeding disorders and informed them of how to refer to new Haemophilia clinics where laboratory testing and treatment were available for the first time. Clinic days were promoted with radio and newspaper adverts.
- Attending the glamorous World Haemophilia Day event at the Glasgow Haemophilia Centre to thank the staff.
- Strengthening the Haemophilia Scotland Women's group, holding regular meetings including in Edinburgh and Glasgow.
- Holding a "Try something new" day for all ages at Crieff Hydro to encourage people with bleeding disorders to stay active and to make connections across the generation. Alex Dowsett, an elite cyclist with haemophilia, attended the event to launch the Miles for Haemophilia campaign.
- Holding a support event for teenagers at the Transition Extreme facility in Aberdeen and promoted a sister Escape Room event run by the Edinburgh Haemophilia Centre.
- Raising awareness of Haemophilia Scotland and our Diagnosis Malawi project with the support of Leith Labs, the Zawadi Women's Choir and our Haemophilia Blood Doctor Crime Scene. Changes were also made to the Haemophilia Scotland constitution to more accurately reflect the international development element of our work.
- Participating in several awareness raising days including,
 - World Hepatitis Day by calling for the early elimination of hepatitis C virus in the Scottish bleeding disorders community and took part in the European Haemophilia Consortium Round Table meeting on the campaign.
 - World AIDS day by remembering those who have been lost to the virus and promoting the Contaminated Blood Memorial Fund.
 - Rare Diseases Day by promoting the Rare Diseases Day photography project and attending the Rare Diseases Day reception at the Scottish Parliament.
 - International Women's Day by sharing stories of women working together to improve healthcare to promote the Haemophilia Scotland Women's Group.

APPENDIX 1

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

Information

Haemophilia Scotland provides accurate, up-to-date, accessible information on all matters related to haemophilia, von Willebrands and other inherited bleeding disorders. We did this

- Providing regular updates of our activities through the blog hosted on the Haemophilia Scotland website. The website received 29,059 hits during the financial year.
- Continuing to add new pages to the website including on the,
 - Contaminated Blood Memorial Fund.
 - Extended Half-life Clotting Factor Products,
 - Welfare and benefits.
- Promoting the Edinburgh Bleeding Disorders Psychological Support Service Pilot and encouraged people who might benefit to ask to be referred. Used an interview conducted by Birchgrove Group to highlight the issues which members could address through the service.
- Raised public awareness of Haemophilia Scotland and inherited bleeding disorders by joining the riding of parliament.
- Providing information on the results of the international SIPPET study which found a lower risk of inhibitors when using plasma derived treatment compared with recombinant treatment.
- Sending a representative to the World Federation of Hemophilia Congress in Orlando to bring back the latest information and prepare to welcome the Congress to Glasgow in 2018.
- Reporting on the European Medicines Agency investigation into the new Direct Acting Antiviral therapies for hepatitis C and informed members about the related work of the Medicines and Health products Regulatory Agency.
- Informing members receiving treatment deliveries at home about the change of ownership of the company concerned.
- Giving members the opportunity to hear about people with bleeding disorders across Europe live through the European Haemophilia Consortium Haemophilia Stories project.

Advocacy

Haemophilia Scotland enables patients and carers to work in partnership with healthcare professional and others to continuously improve the treatment, care, and support available to individuals and families with inherited bleeding disorders in Scotland.

- In partnership with the Scottish Inherited Bleeding Disorders Network, conducting a needs assessment which was used to improve our services and inform the work plan of the network.
- Supporting the Scottish Government in establishing the Scottish Infected Blood Support Scheme by engaging with our members about changes, data protection requirements, and the objectives of the change.
- Ensuring patients were represented on all three Working Groups and the Steering Group of the Scottish Inherited Bleeding Disorders Network.

APPENDIX 1

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

- Meeting with the Cabinet Secretary for Health and worked with the Scottish Government to ensure the smooth establishment of the Scottish Infected Blood Support Scheme. Gave members opportunities to have their questions about the new scheme answered.
- Participating in the Penrose Inquiry Short Life Working Group whose recommendation to try to find the unidentified victims of the contaminated blood disaster were implemented by the Scottish Government in full.
- Responding to the Department of Health consultation on contaminated blood support payments on behalf of our members in Scotland who rely on the English support schemes. Briefed key Scottish MPs in advance of debates on the contaminated blood issue at Westminster.
- Encouraging members to take part in the Department of Work and Pensions review of the Personal Independence Payments (PIP).

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)

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

23/02/18.

Receipts and payments accounts

For the period from

Period start date

Day Month Year

01 April 2016

to

Period end date

Day Month Year

31 March 2017

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	39,671	34,395			74,066	21,683
Legacies	-				-	-
Grants	14,702	23,084			37,786	98,500
Receipts from fundraising activities					-	661
Gross trading receipts					-	-
Income from investments other than land and buildings	21				21	24
Rents from land & buildings					-	-
Gross receipts from other charitable activities					-	-
					-	-
A1 Sub total	54,394	57,479	-	-	111,873	120,868
A2 Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	-
Proceeds from sale of investments					-	-
A2 Sub total	-	-	-	-	-	-
Total receipts	54,394	57,479	-	-	111,873	120,868
A3 Payments						
Expenses for fundraising activities					-	1,009
Gross trading payments					-	-
Investment management costs					-	-
Payments relating directly to charitable activities	103,844	19,032			122,876	51,496
Grants and donations					-	-
Governance costs:					-	-
Audit / independent examination	1,680				1,680	900
Preparation of annual accounts	1,000				1,000	-
Legal costs	1,080				1,080	-
AGM/Conference	3,182				3,182	11,352
					-	-
A3 Sub total	110,786	19,032	-	-	129,818	64,757
A4 Payments relating to asset and investment movements						
Purchases of fixed assets					-	-
Purchase of investments					-	-
A4 Sub total	-	-	-	-	-	-
Total payments	110,786	19,032	-	-	129,818	64,757
Net receipts / (payments)	(56,392)	38,447	-	-	(17,945)	56,111
A5 Transfers to / (from) funds						
Surplus / (deficit) for year	(56,392)	38,447	-	-	(17,945)	56,111

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	99,327	-			99,327	43,216
	Surplus / (deficit) shown on receipts and payments account	(56,392)	38,447			(17,945)	56,111
						-	
	Cash and bank balances at end of year	42,935	38,447	-	-	81,382	99,327

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

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

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

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

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

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

Signature	Print Name	Date of approval
<i>William Wright</i>	WILLIAM WRIGHT	23/02/18

Section C Notes to the Accounts

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

--

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
--	---

Authority under which paid

£

C3b Trustee remuneration - details

C4a Trustee expenses

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

C4b Trustee expenses - details

	Number of trustees	£
Travel & subsistence	2,212	

C5 Transactions with trustees and connected persons

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

C6 Other information

--

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	12,000				12,000	7,541
Baxalta					-	10,000
Other	12,671	6,395			19,066	4,142
Bayer	15,000				15,000	
Swedish Orph		28,000			28,000	
Total	39,671	34,395	-	-	74,066	21,683

2 Grants

	Unrestricted funds to nearest £	Restricted funds to nearest £	Total current period to nearest £	Total last period to nearest £
Scottish Government			-	98,500
Alliance Scotland - Self Management	14,702		14,702	-
Lloyds TSB Foundation		19,875	19,875	-
World Federation of Haemophilia		3,209	3,209	-
Total	14,702	23,084	37,786	98,500

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					-	-
					-	-
					-	-
					-	-
					-	-
					-	-
Total	-	-	-	-	-	-

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	5,395				5,395	4,423
Establishment Costs	10,184				10,184	3,902
Office Expenses	370				370	712
Printing, Postages and Stationary	1,637				1,637	1,844
Subscriptions & Donations	485				485	85
Project costs	25,370	19,032			44,402	12,112
Staff Costs	55,820				55,820	27,104
Marketing Costs	4,322				4,322	693
Bank charges	261				261	621
					-	
					-	
Total	103,844	19,032	-	-	122,876	51,496

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	39,671				39,671	21,683
Legacies					-	
Grants	14,702				14,702	98,500
Receipts from fundraising activities					-	661
Gross trading receipts					-	
Income from investments other than land and buildings	21				21	24
Rents from land & buildings					-	-
Gross receipts from other charitable activities					-	-
Sub total	54,394	-	-	-	54,394	120,868
Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	-
Proceeds from sale of investments					-	-
Sub total	-	-	-	-	-	-
Total receipts	54,394	-	-	-	54,394	120,868
Payments						
Expenses for fundraising activities	950				950	1,009
Gross trading payments					-	
Investment management costs					-	
Payments relating directly to charitable activities	102,894				102,894	51,496
Grants and donations					-	
Governance costs:					-	
Audit / independent examination	1,680				1,680	900
Preparation of annual accounts	1,000				1,000	
Legal costs	1,080				1,080	
AGM & Conference	3,182				3,182	11,352
Sub total	110,786	-	-	-	110,786	64,757
Payments relating to asset and investment movements						
Purchases of fixed assets					-	
Purchase of investments					-	
Sub total	-	-	-	-	-	-
Total payments	110,786	-	-	-	110,786	64,757
Net receipts / (payments)	(56,392)	-	-	-	(56,392)	56,111
Transfers to / (from) funds					-	
Surplus / (deficit) for year	(56,392)	-	-	-	(56,392)	56,111

Nature and purpose of funds

--	--

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	Total restricted funds	Total restricted funds last period
	Malawi	Memorial Fund	Zambia	Teenagers		
Receipts						
Donations	143	6,252		28,000	34,395	
Legacies					-	
Grants	19,875		3,209		23,084	
Receipts from fundraising activities					-	
Gross trading receipts					-	
Income from investments other than land and buildings					-	
Rents from land & buildings					-	
Gross receipts from other charitable activities					-	
Sub total	20,018	6,252	3,209	28,000	57,479	-
Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	
Proceeds from sale of investments					-	
Sub total	-	-	-	-	-	-
Total receipts	20,018	6,252	3,209	28,000	57,479	-
Payments						
Expenses for fundraising activities					-	
Gross trading payments					-	
Investment management costs					-	
Payments relating directly to charitable activities	15,823		3,209		19,032	
Grants and donations					-	
Governance costs:					-	
Audit / independent examination					-	
Preparation of annual accounts					-	
Legal costs					-	
Sub total	15,823	-	3,209	-	19,032	-
Payments relating to asset and investment movements						
Purchases of fixed assets					-	
Purchase of investments					-	
Sub total	-	-	-	-	-	-
Total payments	15,823	-	3,209	-	19,032	-
Net receipts / (payments)	4,195	6,252	-	28,000	38,447	-
Transfers to / (from) funds						
Surplus / (deficit) for year	4,195	6,252	-	28,000	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.
Zambia. A grant was received from the World Federation of Haemophilia to conduct an assessment visit to Zambia for a potential ongoing partnership.
Teenagers. A donation was received from Swedish Orphan Biovitrum Ltd for the Teen Transition Project.

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	2016		31	03	2017
Set out on pages						(remember to include the page numbers of additional sheets)	
Respective responsibilities of trustees and examiner	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.						
Basis of independent examiner's statement	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.						
Independent examiner's statement	In the course of my examination, no matter has come to my attention [other than that disclosed on the attached page*]						
	1. 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 						
	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.						
Signed:					Date:	27/2/18	
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.

APPENDIX 3

Disclosure section

Only complete if the examiner needs to highlight material problems.

Give here brief details of
any items that the
examiner wishes to
disclose