

APPENDIX 1



Office of the Scottish Charity Regulator

Trustees' Annual Report for the period							
Period start date				Period end date			
	Day	Month	Year		Day	Month	Year
From	1	11	2014	To	31	07	2015

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	Susan Warren	Vice Chair & Treasurer	resigned May 2015	
3	Lynn Fraser	Vice Chair		
4	Carolyn McGimpsey	Secretary		
5	Ken Peacock			
6	Hugh MacInnes			
7	Margaret Loughray		resigned May 2015	
8	Nicola Gandy			
9	Jill Peacock	Treasurer	Co-opted July 2015	
10				
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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

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 Association.

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

Support

Haemophilia Scotland provides people individuals and families with bleeding disorders in Scotland with direct support and opportunities to support each other.

The conclusion of the Parent Mentoring Project Pilot was followed by further work in this area. Those involved in the pilot continued to be supported and we worked collaboratively together to implement the learning from the pilot and improve our model for support.

To coincide with the publication of the Penrose Report, Haemophilia Scotland organised a lunch for individuals and families affected. This provided a supportive environment for those trying to come to terms with the content of the Penrose Report. Both the Cabinet Secretary and Minister attended in a non-speaking capacity and took the opportunity to hear from affected families directly about their experiences.

Haemophilia Scotland trustees also travelled to Manchester to support the successful perfect hour record attempt by elite cyclist Alex Dowsett, who has haemophilia. Feedback from members showed that this achievement was particularly inspirational to our younger members.

There was strong feedback that the private Facebook Group for members was providing an invaluable opportunity for peer to peer support.

Members particularly value the ability to support each other outside office hours and the wide variety of experiences of the other members.

Haemophilia Scotland volunteers visited Malawi to establish the potential for a new project to help those with suspected bleeding disorders. The trip included visits to major Haematology departments and meeting the Minister for Health. The visit was a catalyst for the establishment of the Society for Haemophilia and Allied Bleeding Disorders in Malawi. The inaugural "Walk RED Malawi" event was held and raised £1000 for the project. The comparison with Malawi highlights the value of the world class haemophilia services provided in Scotland.

Information

To ensure that information relevant to children and families with bleeding disorders was widely available the Haemophilia Scotland website (www.haemophilia.scot) continued to be developed and expanded. In particular, new advice for those planning to travel abroad was developed with assistance from the Edinburgh Haemophilia Centre.

Traffic to the website grew rapidly during this period culminating in the site being viewed 1387 times in a single day (25 March 2015). Information continued to be supplied over the telephone and email, as well as through social media.

We took part in the European Haemophilia Consortium's (EHC) New Technology Workshop to enable us to provide information to our community, via our website and events, about the development in extended half-life clotting factor products and the progress in gene therapy and Haemophilia A and B.

We also promoted new information from the World Federation of Haemophilia about bleeding disorders and women. Similarly, the EHC Round Table meeting on inhibitors enabled Haemophilia Scotland to provide members with the latest information about this significant potential complication in treatment of bleeding disorders.

Evening webchats were also held to give members a chance to discuss current issue and ask questions in a group format.

Advocacy

Haemophilia Scotland actively engaged with the work of the Scottish Parliament, contributing to meetings of the Cross Party Group on Rarer Diseases and attending the Specialized Healthcare Alliance reception. The high point of this engagement was our reception, held jointly with The Hepatitis C Trust, to highlight the need for the Penrose Report to be

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

published. This was attended by the Minister for Health, Maureen Watt MSP.

We also engaged with the Association of British Pharmaceutical Industries (ABPI) about the use of the Yellow Card notification system and their guidance on working with the pharmaceutical industry. Bio Products Laboratory (BPL) also responded to concerns, raised by Haemophilia Scotland on behalf of members, about the safety of plasma derived clotting factor products in relation to the emerging threat from Ebola. Haemophilia Scotland also made several patient organisation submissions to the Scottish Medicines Consortium in support of applications for the new Direct Acting Antiviral therapies for Hepatitis C. Haemophilia Scotland worked hard to raise public and political awareness of the contaminated blood disaster. In both the run up to the publication of the Penrose Report and following it the charity. Trustees, staff, and volunteers all conducted interviews with Scottish radio, newspapers, and television. Similarly, briefings were developed and disseminated to help members and other interested parties understand the content of the Report. Meetings were held with the Scottish Government, including with the Cabinet Secretary agree a constructive response to the publication. This work included supporting Richard Lyle MSPs parliamentary motion on the Penrose Report (S4M-12139). The Scottish Government response to this work included, apologies from the Cabinet Secretary and First Minister, announcing the National Managed Clinical Network for Inherited Bleeding Disorders, committing to making direct acting antiviral treatment to those who were clinically suitable and infected through the contaminated blood disasters, and establishing a Financial Support Review Group.

The annual meeting between patient representative and the Scottish Haemophilia Centre Directors, was chaired by Haemophilia Scotland's Chair, and was productive. It was agreed that it was likely this would be taken forward in future by a new National Managed Clinical Network for Inherited Bleeding Disorders once formally established. The network was announced a four months later and marked a step change in the constructive working between patients and healthcare professionals in Scotland.

Haemophilia Scotland took part in World Haemophilia Day, travelling to Ireland to take part an EHC event which revealed new research on the impact that patient involvement has on clotting factor purchasing. We also attended the Glasgow Haemophilia Centre vintage tea room event to mark the day. The charity also took part in activities to mark World AIDS Day, Rare Diseases Day, International Women's Day, and International Nurses' Day.

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.

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Details of any deficit

Haemophilia Scotland does not have a deficit.

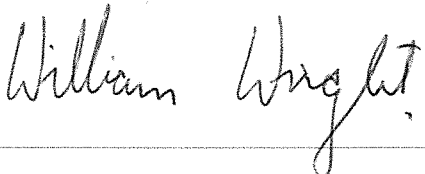
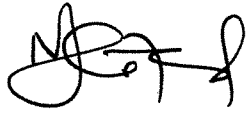
Donated facilities and services (if any)

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)		
Full name(s)	WILLIAM WRIGHT	NICOLA GANDY
Position (e.g. Chair)	CHAIR	TRUSTEE
Date	28/9/16	29/9/16

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Receipts and payments accounts							
For the period from	Period start date			to	Period end date		
	Day	Month	Year		Day	Month	Year
	01	November	2014		31	July	2015

Section A Statement of receipts and payments

	Unrestricted funds to nearest £	Restricted funds to nearest £	Expendable endowment funds to nearest £	Permanent endowment funds to nearest £	Total funds current period to nearest £	Total funds last period to nearest £
A1 Receipts						
Donations	7,615				7,615	26,318
Legacies					-	-
Grants	45,000				45,000	92,305
Receipts from fundraising activities					-	-
Gross trading receipts					-	-
Income from investments other than land and buildings	13				13	15
Rents from land & buildings					-	-
Gross receipts from other charitable activities					-	340
					-	-
A1 Sub total	52,628	-	-	-	52,628	118,978
A2 Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	-
Proceeds from sale of investments					-	-
A2 Sub total	-	-	-	-	-	-
Total receipts	52,628	-	-	-	52,628	118,978
A3 Payments						
Expenses for fundraising activities					-	-
Gross trading payments					-	-
Investment management costs					-	-
Payments relating directly to charitable activities	45,834				45,834	83,068
Grants and donations					-	-
Governance costs:					-	-
Audit / independent examination	150				150	-
Preparation of annual accounts					-	-
Legal costs					-	-
Other					-	-
					-	-
A3 Sub total	45,984	-	-	-	45,984	83,068
A4 Payments relating to asset and investment movements						
Purchases of fixed assets					-	-
Purchase of investments					-	-
A4 Sub total	-	-	-	-	-	-
Total payments	45,984	-	-	-	45,984	83,068
Net receipts / (payments)	6,644	-	-	-	6,644	35,910
A5 Transfers to / (from) funds						
					-	-
Surplus / (deficit) for year	6,644	-	-	-	6,644	35,910

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)	
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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	8	3,001

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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Additional analysis (2)

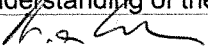
5 Breakdown of unrestricted funds

	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	7,615				7,615	26,318
Legacies					-	-
Grants	45,000				45,000	92,305
Receipts from fundraising activities					-	-
Gross trading receipts					-	-
Income from investments other than land and buildings	13				13	15
Rents from land & buildings					-	-
Gross receipts from other charitable activities					-	340
Sub total	52,628	-	-	-	52,628	118,978
Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	-
Proceeds from sale of investments					-	-
Sub total	-	-	-	-	-	-
Total receipts	52,628	-	-	-	52,628	118,978
Payments						
Expenses for fundraising activities					-	-
Gross trading payments					-	-
Investment management costs					-	-
Payments relating directly to charitable activities	45,984				45,984	83,068
Grants and donations					-	-
Governance costs:					-	-
Audit / independent examination					-	-
Preparation of annual accounts					-	-
Legal costs					-	-
Sub total	45,984	-	-	-	45,984	83,068
Payments relating to asset and investment movements						
Purchases of fixed assets					-	-
Purchase of investments					-	-
Sub total	-	-	-	-	-	-
Total payments	45,984	-	-	-	45,984	83,068
Net receipts / (payments)	6,644	-	-	-	6,644	35,910
Transfers to / (from) funds					-	-
Surplus / (deficit) for year	6,644	-	-	-	6,644	35,910

Nature and purpose of funds						
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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	11	2014		31	07	2015	
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*]							
	<p>1. which gives me reasonable cause to believe that in any material respect the requirements:</p> <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> <p>2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.</p>							
Signed:						Date:	11/11/2016	
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**

A large, empty rectangular box with a dotted border, occupying most of the page below the instructions. It is intended for the user to provide details of items for disclosure.