



Trustees' Annual Report for the period

Period start date				Period end date			
From	Day	Month	Year	To	Day	Month	Year
	01	08	2015		31	03	2016

Office of the Scottish Charity Regulator

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	Lynn Fraser	Vice Chair		
3	Jill Peacock	Treasurer	Co-opted July 2015	
4	Carolyn McGimpsey	Secretary		
5	Ken Peacock			
6	Hugh MacInnes			
7	Nicola Gandy			
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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

Support

Children and Families were given an opportunity to meet each other and form supportive peer to peer mentoring links at our Pirate Golf Day. A similar swimming extravaganza was held later in the year with support from the specialist physiotherapist from the Edinburgh Haemophilia Centre and with Jack Bridge, Haemophilia Paralympic swimmer, as our special guest. The event launched a new information resource on the importance of an active lifestyle for children and young people with bleeding disorders.

Our first Women's Day event was held in Glasgow and was used to establish that there was demand for a women's group.

The mentoring work of Haemophilia Scotland adopted a new model and language. Describing the peer to peer relationships formed as links made it clear that they were mutually beneficial.

Support was also provided to those affected by the contaminated blood disaster with a Memorial Event. Participants included bereaved families, effected people and their families. It was attended by the First Minister, Deputy First Minister, and Cabinet Secretary. The event marked the launch of a contaminated blood memorial fund which is raising money to build a lasting memorial to the victims of the contaminated blood disaster in Scotland.

An event was held for adults with bleeding disorder at Go Ape. The event sought to encourage an active lifestyle and to provide an opportunity for younger adults to meet.

Information

Haemophilia Scotland presented the Scottish case study at the Irish Haemophilia Society's European Hepatitis C Conference. This event also provided us with the latest information on the treatment of hepatitis for our members. This built on the information already provided at our Hepatitis C Information day. Further information was gathered by our Chair at the World Hepatitis Summit in Glasgow.

As members of the Scottish Contaminated Blood Financial Support Review Group we were able to provide detailed information of its work on our website. The minutes from all meetings were published as soon as they were available.

The Haemophilia Scotland website (www.haemophilia.scot) continued to grow with regular updates and new information pages. A new facility was launched to let visitors see which publications produced by third parties and Haemophilia Scotland were available for order. There was an increased emphasis on responding to breaking events, for example, ensuring people had the information they needed during the closure of the Forth Road Bridge. Additional information was also added including guidance on dental health.

Our first Annual General Meeting as a Scottish Incorporated Charitable Organisation (SCIO) was held as part of a residential Gathering and Conference. This event provided a wide variety of information and discussion sessions covering topics ranging from dentistry and the new Network to psychosocial support and relaxation techniques. There was also a keynote presentation on understanding inhibitor risks from the Chair of the United Kingdom Haemophilia Doctors Organisation Working Party of Inhibitors.

Advocacy

Haemophilia Scotland presenting a briefing on the Penrose Report to the Scottish Parliament Cross Party Group on Rare Diseases which stressed the need to pay attention to risk and safety when seemingly life changes advances are made in the treatment for rare conditions. Our media work also continued to keep the contaminated blood disaster in the media while a way forward was agreed. Articles ran in several major Scottish

APPENDIX 1

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

newspapers. Our engagement with the Scottish Parliament continued with a submission to the Health and Sport Committee's enquiry into the proposed Duty of Candour.

We were represented on the Scottish Contaminated Blood Financial Support Review Group by our Chair and CEO, two campaigning Haemophilia Scotland members were also members of the group in their own right. Haemophilia Scotland conducted the consultation exercise on behalf of the group which included holding six meetings for those affected to have their say across Scotland. A consultation survey was also conducted and analysed and the results of the exercise directly influenced the recommendations of the Group. In parallel to the Group, Haemophilia Scotland advocated for an interim augmented winter fuel payment to be made. Although this proposal was supported by the Scottish Government it was not blocked by lack of support from elsewhere in the UK. Once the Group produced recommendations, Haemophilia Scotland advocated for their rapid implementation. To address the needs of those infected in England but living in Scotland, Haemophilia Scotland also made a submission to the Department of Health (England) consultation on financial support payments. Our Chair gave evidence to the Scottish Parliament Health and Sport Committee when it enquired into what progress had been made in response to the Penrose Report. The committee secured an assurance from the Cabinet Secretary that eligibility criteria for support would be reviewed.

The National Managed Clinical Network for Inherited Bleeding Disorders, also known as the Scottish Inherited Bleeding Disorders Network, was launched. Haemophilia presented on patient expectations at the launch and was central to discussion about the structure of the Network.

Haemophilia Scotland promoted the work of the Network and encouraged patient and parents to join the working groups.

Our patient organisation submissions to the Scottish Medicines Consortium continued to support the approval and introduction of direct acting antiviral treatment for Hepatitis C. Access to treatment for those with genotype 3 was particularly highlighted.

Public awareness of bleeding disorders was raised by participating in the Miles for Haemophilia campaign. The increased effort in awareness raising was demonstrated by our participation in two International Science Festivals with our crime scene display which increased knowledge about bleeding disorders.

Haemophilia Scotland also joined a wide variety of charities working with people with hepatitis C at the World Hepatitis C day in Glasgow. Other awareness days supported included Self-Management Week, World AIDS Day, Rare Diseases Day, International Women's Day, and Rare Diseases Day.

Haemophilia Scotland served on a National Procurement group working on the tender for the home delivery contract.

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.

APPENDIX 1

Details of any deficit

Haemophilia Scotland does not have a deficit.


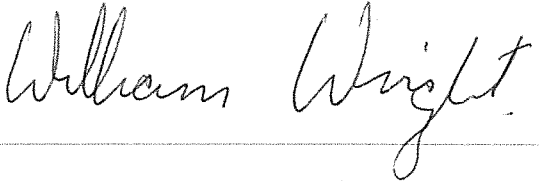
Donated facilities and services (if any)

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)	NICOLA GANDY	WILLIAM WRIGHT
Position (e.g. Chair)	TRUSTEE	CHAIR
Date	15 SEPTEMBER 2016	28/9/16

Receipts and payments accounts

For the period from	Period start date			to	Period end date		
	Day	Month	Year		Day	Month	Year
	01	August	2015		31	March	2016

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	21,683				21,683	7,615
Legacies					-	-
Grants	98,500				98,500	45,000
Receipts from fundraising activities	661				661	-
Gross trading receipts					-	-
Income from investments other than land and buildings	24				24	13
Rents from land & buildings					-	-
Gross receipts from other charitable activities					-	-
					-	-
A1 Sub total	120,868	-	-	-	120,868	52,628
A2 Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	-
Proceeds from sale of investments					-	-
A2 Sub total	-	-	-	-	-	-
Total receipts	120,868	-	-	-	120,868	52,628
A3 Payments						
Expenses for fundraising activities	1,009				1,009	-
Gross trading payments					-	-
Investment management costs					-	-
Payments relating directly to charitable activities	51,496				51,496	45,834
Grants and donations					-	-
Governance costs:					-	-
Audit / independent examination	900				900	150
Preparation of annual accounts					-	-
Legal costs					-	-
AGM/Conference	11,352				11,352	-
					-	-
A3 Sub total	64,757	-	-	-	64,757	45,984
A4 Payments relating to asset and investment movements						
Purchases of fixed assets					-	-
Purchase of investments					-	-
A4 Sub total	-	-	-	-	-	-
Total payments	64,757	-	-	-	64,757	45,984
Net receipts / (payments)	56,111	-	-	-	56,111	6,644
A5 Transfers to / (from) funds						
					-	-
Surplus / (deficit) for year	56,111	-	-	-	56,111	6,644

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	1,664

C5 Transactions with trustees and connected persons

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

C6 Other information

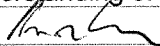
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Additional analysis (2)**5 Breakdown of unrestricted funds**

	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	21,683				21,683	7,615
Legacies					-	-
Grants	98,500				98,500	45,000
Receipts from fundraising activities	661				661	-
Gross trading receipts					-	-
Income from investments other than land and buildings	24				24	13
Rents from land & buildings					-	-
Gross receipts from other charitable activities					-	-
Sub total	120,868	-	-	-	120,868	52,628
Receipts from asset & investment sales						
Proceeds from sale of fixed assets					-	-
Proceeds from sale of investments					-	-
Sub total	-	-	-	-	-	-
Total receipts	120,868	-	-	-	120,868	52,628
Payments						
Expenses for fundraising activities	1,009				1,009	-
Gross trading payments					-	-
Investment management costs					-	-
Payments relating directly to charitable activities	51,496				51,496	45,834
Grants and donations					-	-
Governance costs:					-	-
Audit / independent examination	900				900	150
Preparation of annual accounts					-	-
Legal costs					-	-
AGM & Conference	11,352				11,352	-
Sub total	64,757	-	-	-	64,757	45,984
Payments relating to asset and investment movements						
Purchases of fixed assets					-	-
Purchase of investments					-	-
Sub total	-	-	-	-	-	-
Total payments	64,757	-	-	-	64,757	45,984
Net receipts / (payments)	56,111	-	-	-	56,111	6,644
Transfers to / (from) funds					-	-
Surplus / (deficit) for year	56,111	-	-	-	56,111	6,644
Nature and purpose of funds						

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	08	2015		31	03	2016
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:	11/10/2016	
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**

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