OSCII Office of the Scotlish Charity Regulator	HAEMOPHII	IA SCOTLAI	nter dişirdiy namini iz ND	\$ 2 Jen	A Comment of the succession		SC044298
	For the period from	Feneral Man		to	Posteries   Post	-	
apara Landrida ya kana ya kata ka mada ka maka ka			I I I I I I I I I I I I I I I I I I I			السعنييين المسيس	Armania de la compania del compania de la compania del compania de la compania del compania de la compania de la compania de la compania del compania de la compania del compania de la compania del compania de la compania del c
Section A Statement of re	eceipts and p	payments	Expendable		Permanent		
	Unrestricted funds	Restricted funds	endowment funds		endowment funds	Total funds current period	Total funds last period
	(o nearest E	to nearest E	to nearest E		to nearest £	to nearest £	to nearest E
A1 Receipts							
Donations	3,340	17,500		_,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		20,840	12,800
Legacies						•	
Granis	170,000	5,951		L.,.		175,951	108,875
Receipts from fundraising activities	3,910	12,938				16,848	14,624
Gross trading receipts			-				_
Income from investments other than and and buildings	117			ļ		117	8.
Rents from land & buildings Gross receipts from other charitable activities						**************************************	*
	,			ļ.,		*****	138,305
A1 Sub total	177,367	36,389			The second secon	213,786	136,300
A2 Receipts from asset & investment sales		-		ļ. -			
Proceeds from sale of fixed assets		<u> </u>				*	<u> </u>
Proceeds from sale of investments A2 Sub total	-	•			•	•	Y
Total receipts	177,367	38,389		_		213,756	138,305
A3 Payments			and a first on Astronomeropolis	-			and the state of t
Expenses for fundraising activities	2,837			and miles		2,837	1,056
Gross trading payments						4	
Investment management costs				1			
Payments relating directly to charitable activities	105,705	51,586				157,291	110,927
Grants and donations						•	
Governance costs:				_		•	
Audit / independent examination				_		*	900
Preparation of annual accounts	:1,000			<u> </u>		1,000	1,000
Legal costs				<u> </u>		*	<u> </u>
AGM/Conterence	508			-		508	4,384
A3 Sub total	110,050	51,546				161,636	118,277
A4 Payments relating to asset and investment movements				ļ			
Purchases of fixed assets				-	<u> </u>	•	1
Purchase of investments  A4 Sub total				-		*	
The second secon	-	•	*		•		441.097
Total payments	110,050	51,586	-	1	•	161,636	118,277
Net receipts / (payments)	67,317	(15,197)		1_		52,120	18,02
A5 Transfers to / (from) funds	(10,747)	10,747				•	•
Surplus / (deficit) for year	56,570	(4,450)			•	52,120	18,027

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	9							
		Peri	od start o	date		Per	iod end (	
		Day	Month	Year		Day	Month	Year
F	rom	01	04	2018	То	31	03	2019
			:					
1					1			1

Office of the Scottish Charity Regulator

## Reference and administration details

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

Haemophilia Scotland	and the second s
SC044298	and the second s
SCVO Charity Business Hub, 4th	Floor, Hayweight House,
23 Lauriston Street	and the state of t
Edinburgh	
Scotland, UK	Postcode EH3 9DQ

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

		The translation of the same of	
		net for whole goes	
Bill Wright	Chair		Annual Application (All Prints and All Annual Applications and Annual Applicat
Lynne Black	Vice Chair	agus propagan sa	Company of the Compan
James Geekie	Treasurer	Co-opted 18 August 2018 & Elected 8 June 2019	and the state of t
Carolyn McGimpsey	Secretary		And the second s
Nikki Gandy		. Name in the second of the se	
Hugh MacInnes		The garage and the state of the	
Nancy Brodie	and the second s	policy on high time and the company of the company	The state of the s
John Dearden		Elected 8 June 2019	
Gregor MacInnes		Elected 8 June 2019	and the state of t
	The second secon	To the control of the	Landin of the same of the same
		and the second s	
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garagen videlassadagitetaring ginna andaran videlan videlan kanada da ataun kanada videlan da sanada sanada sa	And the second s		
Angeles and the second	a jugad sa a dinaminandi <b>di</b> njama ka ana tara na dinya <del>dinya dinamina indamina</del> a a di wasa na tara na dinamina di wasa na d	managata (Prog. 4 Sec. )	

### 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)

	District the property of the p
Lynn Fraser	Resigned 1 August 2018
Dan Hewins	Resigned 19th May 2018
Heather MacLeod	Resigned 19th 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;

- 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 aims to provide a way for all people with haemophilia, von Willebrand Disease and other bleeding disorders in Scotland to meet, share experiences, learn from one another and offer mutual support.

To achieve this in this period we held a programme of support events. To make it easier for children and families outside the central belt we held a well-attended family day at Landmark in Aviemore. Our teenagers took part in a residential sailing challenge off the south coast of England. The trip had an underline message of taking responsibility and participants were responsible for getting their own treatment through security at the airport. The teenagers took part in our second annual go-karting championship at Knockhill, our climbing event at Ratho, and a jamming session in Glasgow. These events were designed to draw the teenagers together as a group. A Pad Production Day run by our Women's Group helped 30 women in rural Kenya manage their bleeding. Our Twinning work with the Kenya Haemophilia Association (KHA) was recognised with a prize from the World Federation of Hemophilia (WFH).

### Information

Haemophilia Scotland aims to provide accurate, up-to-date, accessible information on all matters related to haemophilia, von Willebrand Disease and other bleeding disorders. We do this with individuals over the phone, by email, and on social media. We held a patient information day focusing on new and emerging therapies in Dundee. We maintained patient friendly website which was visited 13,551 times by 8,367 users. As well as keeping our visitors informed about our work, we covered a wide variety of issues including the bacteria outbreak at NHS GGC, the availability of the flu vaccine, the Department of Work and Pensions review of Haemophilia PIP cases, and the introduction of the Scottish Carer's Allowance Supplement. We provided information about the potential impacts of Brexit to the provision of treatment and care for bleeding disorders in Scotland.

We provided information on opportunities for our members to support one another such as when the Andy Gunn Band played in Leith. We highlighted where people with bleeding disorders are being successful in their chosen field, such as the elite cyclist, Alex Dowsett, getting close to the medals at the European Championships in Glasgow or Jay Gardener taking control of his health though exercise. We promoted the Sobi Hello Haemophilia photo competition and noted that all the winners came from Scotland.

### Advocacy

Haemophilia Scotland aims to facilitate progressive influential relationships with the medical establishment, voluntary sector intermediaries, government agencies, similar UK organisations and international partners.

The majority of our work in this field in this period was related to the contaminated blood products disaster. We worked closely with the Scottish Infected Blood Forum to respond to the establishment of a statutory UK Public Inquiry. Following consultation with our members we produced a joint response to Infected Blood Inquiry terms of reference consultation and helped members respond to the first call for evidence. We then successfully applied to become a core participant of the Inquiry and attended the opening hearings in London. We contributed to the opening statement from our QC. We successfully called for the Scottish Government to become a core participant of the Inquiry. Again working

### **APPENDIX 1**

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

with the Scottish Infected Blood Forum we held campaign meetings in July and March to covering the Inquiry and the continued development of the Scottish Infected Blood Support Scheme (SIBSS), in particular the conclusion and implementation of the Scottish Government Clinical Review of the impart of Hepatitis C. We supported a motion tabled in the Scottish Parliament calling for better funding of new chronic payments from the SIBSS. In combination with direct lobbying of the Scottish Government more money was identified for these payments. Our Chair, Bill Wright was one of those who met with the Ministers from the Cabinet Office and Department of Health (England) to discuss the need for interim payments to alleviate financial hardship for the duration of the Infected Blood Inquiry. We worked on issues not related to contaminated blood products including advocating on behalf of individual members. We campaigned with our members, especially in the West of Scotland, on the issue of NHS GGC deciding to move Scotland's largest Haemophilia Centre to smaller and less accessible accommodation without any patient consultation. We continued to liaise with Scottish MPs and MSPs including a visit to our offices by our local MP. We took part in the Scottish Inherited Bleeding Disorder SIBDN Network event in Glasgow in December. We responded to the Scottish Government consultation on disability assistance highlighting the needs of people with bleeding disorders. We promoted the Scottish Parliament's Health and Sport Committee's major inquiry into the future of primary care in Scotland to ensure the voices of those with rare bleeding disorders were heard.

Capacity

Haemophilia Scotland aims to be a strong and sustainable organisation and are grateful to the Scotlish Government, our pharmaceutical supporters, and other grant giving bodies who support our work. We are particularly grateful to the members of our community who take part in community fundraising to support our work or raise money for the Contaminated Blood Memorial Fund that we host. We even had more brave people completing parachute jumps to raise much needed funds. This year an amazing £7,030 raised for the contaminated blood memorial fund by the Harburn Golf Club.

### 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**

AFFERDIA		
Details of any deficit	Haemophilia Scotland does not have a deficit.	
Donated facilities and se	ervices (if any)	
	Commence of the second	
Other optional info	ormation	
Other optional init		With the designation of the second
		Acceptation of the contract of
		man and company of the resonant encyclosing with
		Contract of the Contract of th
Declaration		
The trustees declare the Signed on behalf of the	at they have approved the trustees' report above.	
Signature(s)	William Unght.	V-104
Full name(s)	WILLIAM WRIGHT.	
Position (e.g. Chair)	CHAIR. 04/03/20.	
Date	04/03/20.	

SC044298

Section D. Clark					emineral de la companya de la compa	OCU44280	)
Section B Stateme	Details	Unrestricted funds	Restricted funds	Expendable endowment funds	Permanent endowment funds	Total current	Total last perio
B1 Cash funds	Cash and bank balances at start of year	1 to nearest E	to nearest £	10 nearest E	to nearest E	to nearest £	to nearest £
the control of the co	Surplus / (deficit) shown on receipts and	52,426	46,984			99,410	81,382
*	payments account	56,570	(4,450)			62,120	18,028
						•	
	Cash and bank balances at end of year	108,996	42,834			161,630	99,410
	(Agree balances with receipts and payments account(s))		3			2.2.2.2.3.3.3.3.3.3.3.3.3.3.3.3.3.3.3.3	
	- च्या चारा व <b>ाल्या । व्या</b>						
	Details			Fund to which	asset belongs	Market valuation	Last year
2 Investments		:		1		to nearest £	to nearest E
					****		
	engal services				Total	<u> </u>	
3 Other assets	Details		Fund to which	asset belongs	Cost (if available) to nearest £	Current value (if available) to nearest £	Last year to nearest £
				·			
			***************************************		minute de la companya del companya del companya de la companya de		<u> </u>
							<del></del>
	The state of the s						
		į		Total	:4		
	Details			Fund to which I	lability relates	Amount due	Last year
4 Liabilities			1		***************************************	to nearest 2	to nearest £
				**************************************			
				and the state of t			
			, ,	<del></del>	Total		
	Manuto		•	<b>*</b>		Amount due	
Annella mand History	Details			Fund to which it	ability relates	(estimate) to nearest £	Last year to nearest £
Contingent liabilities							10 Healest F
			ŀ				
			L	the state of the s	Total		
ned by one or two trustees					1	J L	
sehalf of all the trustees	Signature	<u> </u>	e de la companya de l	Print Name			Date of approval
	William Who ly		WILLIAM	WRIGH	11		24/08/20
	1			······································	**************************************		114-1
			*************			- 11	

Section C Notes to the	Accounts			
C1 Nature and purpose of funds (may be stated on analysis of funds worksheets)				
	Type of activity or project supported	Individual / Institution	Number of grants made	E <sup>-</sup>
C2 Grants				
			Total	*
C3a Trustee remuneration	If no remuneration was paid during the period to ar trustee cross this box (otherwise complete section 3	ny charity trustee or person 3b)	n connected to a	*
	hich paid		ε	
C3b Trustee remuneration - details				
			·	
C4a Trustee expenses	If no expenses were paid to any charity trustee dur (otherwise complete section 4b)	ing the period then cross	this box	
			Number of trustees	£
C4b Trustee expenses -	Travel & subsistence		2	1,914
uriana				
		and the state of t		
	Nature of relationship Natu	re of transaction	Transaction amount (£)	Balance outstanding at period end (£)
C5 Transactions with trustee and connected persons	The state of the s			
C6 Other Information				
ত কু কুলোচ্চার কুট্টেস্কার বিশ্বস্থানী নি				
	The state of the s			

SC044298

# Additional analysis (1)

### Analysis of receipts and payments

### 1 Donations

	Unrestricted funds to nearest E	Restricted funds	Expendable endowment funds to nearest £	Permanent endowment funds to nearest £	Total current period	Total last period
Pfizer	] [	7,500		<u> </u>	7,500	600
Behring		5,000			5,000	
Trust	2,500	5,000			The state of the s	3,500
Bayer	1	3,000			7,500	1,000
NHS	<b> </b>				1 -1	500
	530				530	1,000
Swedish Orph	310				310	
Total	3,346	17,500		•	20,840	6,200 <b>12,80</b> 6

### 2 Grants

	Unrostricted funds to regrest £	Restricted funds to nearest £
Scottish Government	170,000	
World Federation of Haemophilia		5,951
Total	170,000	5,951

Total current period to nearest £	Total last period
170,000	108,500
5,951	2,376
•	
178,081	100,075

### 3 Gross receipts from other charitable activities

	Unrestricted funds to nearest £	Restricted funds	Expendable endowment funds to nearest £	Permanent andowment funds to nearest E	Total current period to neurest £	Total last period
Other	4,027	12,938			16,965	14,624
Total	4,027	12,938	JP -	<b>*</b>	16,965	14,624

### 4 Payments relating directly to charitable activities

	Unrestricted funds	Restricted funds	Expendable endowment funds	Permanent endowment funds	Total current period	Total last period	
and the second s	to nearest E	to nearest E	to nearest £	to nearest £	to nearest £	to nearest E	
Travel & Subsistence	8,982						
Establishment Costs	14,489	***************************************	<u></u>		8,982	9,962	
Office Expenses	716				14,489	12,537	
Printing, Postages and Stationary	2,598				716	488	
Subscriptions	561				2,598	824	
Project costs					561	1,020	
Slaff Costs	3,639	10,411			13,950	26,001	
Marketing Costs	73,026	11,977			85,003	55,057	
Bank charges	1,368				1,368	1,617	
World Congress	427				427	411	
TYAN CONGRESS		29,198			29,198	3,010	
Total	<u> </u>					•	
12 White	105,708	51,586	•		157,292	110,927	

Additional analysis (2)						
5 Breakdown of unrestricted funds	Unrestricted fund 1 - enter name of fund 'autow	Unrespicted faut 2 - epier name of faut holdw	Universitied fund 3 - Enfect name of Fond fellow	Unrestricted fund 4 - outer raine of fund below	Total unrestricted funds	Total unrestricted funds last period
Receipts  Donations  Legacies  Grants  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	3,340 170,000 3,910 117				3,340 170,000 3,910 117 - - 177,367	1,600 - 100,000 7,172 - 6 - 108,778
Receipts from asset & Investment sales Proceeds from sale of fixed assets Proceeds from sale of investments  Sub total  Total receipts	177,367				177,367	106,778
Payments Exponses for fundraising activities Gross trading payments Investment management costs Payments relating directly to charitable activities Grants and donations Governance costs: Audit / independent examination Preparation of annual accounts Legal costs AGM & Conference	1,000 508				2,837 	1,068 
Payments relating to asset and investment movements Purchases of fixed assets Purchase of investments Sub total Total payments	110,050				110,080	97,131
Net receipts / (payments)  Transfers to / (from) funds  Surplus / (deficit) for year  Nature and purpose of funds	(10,747)				(10,747)	(2,156)

APPENDIX 2

# oscr

Office of the Scottish Charlty Regulator

		epenaen	it exami	ners r	eport c	on the	accoul	NTS V2
Report to the trustees/members of	Charity name Haemophilia Scotland							
Registered charity number	SC044298							
On the accounts of the	Period start date Period end date							
charity for the period	Day	Month	Year			Day	Month	Year
	01	04	2018	to		31	03	2019
Set out on pages	(remember to Include the page numbers of additional sheets)							
Respective responsibilities of trustees and examiner	with the te Charitles A audit requi is my resp	rms of the Cl Accounts (Sc Irement of Re	haritles and otland) Reg egulation 10 examine the	Trustee li ulations 2 (1) (d) of accounts	nvestment 006. The the Accou as require	t (Scotla charity t nts Reg ad unde	and) 2005 A trustees cor gulations do er section 44	in accordance ct and the islder that the es not apply, It i(1) (c) of the
Basis of independent examiner's statement	Accounts ( accounting those reco accounts a procedure	rds. It also in and seeks ex	egulations 2 ot by the cha ocludes cons planations for o do not prov	2006. An earity and a sideration from the trivide all the	examination comparistof of any un custees co e evidence	n includence on of the usual ite number of the usual ite number of the usual includes the	les a review le accounts lems or discl g any such ould be requ	
Independent examiner's statement	<ol> <li>In the course of my examination, no matter has come to my attention [other than that disclosed on the attached page*]</li> <li>which gives me reasonable cause to believe that in any material respect the requirements:         <ul> <li>to keep accounting records in accordance with section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and</li> <li>to prepare accounts which accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations</li> </ul> </li> <li>have not been met, or</li> <li>to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.</li> </ol>							
Signed:		Colon a	io docount	to no roa	Date:		10 3 200	ngarantang dinggalahkan di di danggaran mananang manasa ang
Name:	Trowbar.	B Wilson	• • • • • • • • • • • • • • • • • • •		Date.		10 (3/2/2	-0
	Andrew 1	2 MITSOII		·····	******			
Relevant professional qualification(s) or body (if any):	CA							
Address:	Nelson (	Gilmour S	mith					
	Mercantile Chambers							
	53 Bothwell Street							
	Glasgow G2 6TB							
	GLASGOW	GZ OTB	Mary from the state of the stat	normalis i la communicación la actua	The section of the definition of the section of the section of	*** *** <b>*</b> #####*****	alian anno anno ann ann ann ann ann ann ann	ina de caralita de la participato de productiva de participa de la productiva della della della della della
	6 6 18.11							

<sup>\*</sup>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