

SUPERFICIAL SIDEROSIS - THE SILENT BLEED

England & Wales · Charity number 1169340

Details

Status Registered

Legal form CIO

Registered 2016-09-26

Register [View on the Charity Commission register](#)

Contact

Address 1 Laburnum Close
Aldershot
Hampshire
GU11 3DX

Phone 07870625357

Email silentbleed101@gmail.com

Website www.thesilentbleed.co.uk

Activities

Objects: (A) FOR THE PUBLIC BENEFIT, TO ADVANCE EDUCATION OF EVERYONE ABOUT THE RARE DISEASE SUPERFICIAL SIDEROSIS - SPECIFICALLY SUFFERERS OF THE DISEASE, THEIR CARERS AND THEIR PHYSICIANS. TO ALSO HELP FUND ONGOING, ESTABLISHED AND NEW MEDICAL AND SCIENTIFIC RESEARCH INTO SUPERFICIAL SIDEROSIS, BY PROVIDING GRANTS AND ESTABLISHING NETWORKS OF PROFESSIONALS AND PATIENTS THROUGH OUR WEBSITE AND SOCIAL MEDIA.(B) TO ADVANCE HEALTH AND SAVE LIVES THROUGH: INFORMATION DISSEMINATION TO SUPERFICIAL SIDEROSIS SUFFERERS, CARERS AND THEIR PHYSICIANS; IN ORDER TO SUPPORT SUFFERERS IN GETTING ACCESS TO THE MEDICAL CARE AND TREATMENTS THEY NEED. WE WILL DO THIS THROUGH OUR WEBSITE, PRINTED LEAFLETS AND OTHER MATERIAL AND BY ORGANISING SOCIAL AND VIRTUAL EVENTS USING SOCIAL MEDIA.(C) THE RELIEF OF THOSE IN NEED BY REASON OF DISABILITY BY PROVIDING ADVICE AND EMOTIONAL SUPPORT TO SUFFERERS, THEIR CARERS AND PHYSICIANS. WE WILL DO THIS THROUGH OUR WEBSITE, PRINTED LEAFLETS AND OTHER MATERIAL AND BY ORGANISING SOCIAL AND VIRTUAL EVENTS USING SOCIAL MEDIA.(D) THE CHARITY IS FOR THE BENEFIT OF SUPERFICIAL SIDEROSIS SUFFERERS, THEIR CARERS AND THEIR PHYSICIANS WORLDWIDE, NOT JUST IN THE UK.

Activities: We offer guidance and support to those with Superficial Siderosis, their families, friends, carers and physicians. The charity was developed to aid those with this rare neurological condition to share, network

and find further information. We raise funds for research into finding a cure for the disease.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, The General Public/mankind

Geography

- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-09-30	£5,777	£13,748	-	-
2024-09-30	£6,430	£5,581	-	-
2023-09-30	£2,338	£1,077	-	-
2022-09-30	£1,858	£342	-	-
2021-09-30	£5,102	£4,274	-	-

Trustees

Name	Role	Appointed
JASON KELVIN ROBERTS	Chair	2014-08-15
Sydney-James Fearn-Roberts		2019-03-04

SUPERFICIAL SIDEROSIS - THE SILENT BLEED

England & Wales - Charity number 1169340

Accounts

Trustees' annual report for the period



CHARITY COMMISSION
FOR ENGLAND AND WALES

Period start date Period end date

Charity name Charity No (if any)

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	For the public benefit, to advance the education of everyone about the rare condition Superficial Siderosis—specifically suffers of the condition, their carers, and their physicians.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	Education, research, support and community. The charity continues to push for greater awareness by printing written materials, organises events throughout the year to raise money, volunteers with both those who have Superficial Siderosis and their carers and family via email, personal message, telephone and occasionally face-to-face
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees have reviewed the latest available guidance for trustees from the Charities Commission and have confirmed that they work within it. For example, when using money for printed materials, website running costs or buying consumables, the trustees have shown due prudence in making sure that we've obtained the best price, made efficiencies, not wasted materials and made sure they've considered value for money.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	
Policy on social investment including program related investment	Para 1.38	
Contribution made by volunteers	Para 1.38	
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<p>Education & awareness: Website constantly updated with up-to-date Q&A advice from Dr Levy. Fundraising wristbands and information leaflets dispatched around the world.</p> <p>Research: we're excited and honoured to be part of a UK-based research project through Perspectum.</p> <p>Support: Members supported in a closed social media group for carers and family as well as hundreds of individual private conversations with people affected by Superficial Siderosis</p>

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Achievements against objectives set	Para 1.41	
Performance of fundraising activities against objectives set	Para 1.41	
Investment performance against objectives	Para 1.41	
Other		

Financial Review

	SORP reference	
Review of the charity's financial position at the end of the period	Para 1.21	Due to the founder struggling with health issues, he has had to pay others to assist with the role, therefore wages have gone up this year. It is clear that the expenditure outways the income of the charity, but Jason wishes to keep going as we have done further research to get more donations over the next year.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The charity keeps an amount in reserve every year. This is to cover modest, regular running costs such as printing leaflets and paying for website hosting.
Amount of reserves held	Para 1.22	£500
Reasons for holding zero reserves	Para 1.22	
Details of fund materially in deficit	Para 1.24	
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	Due to the founder struggling with health issues, he has had to pay others to assist with the role, therefore wages have gone up this year. It is clear that the expenditure outways the income of the charity, but Jason wishes to keep going as we have done further research to get more donations over the next year.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
The charity's principal sources of funds (including any fundraising)	Para 1.47	The charity is funded by fundraisers and individual gifts, largely through the website (some regular ,some one-off).
Investment policy and objectives including any social investment policy adopted	Para 1.46	
A description of the principal risks facing the charity	Para 1.46	
Other		

Structure, Governance and Management

Description of charity's trusts:	SORP reference	
Type of governing document (trust deed, royal charter)	Para 1.25	Foundation model constitution
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	By appointment

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policies and procedures adopted for the induction and training of trustees	Para 1.51	
The charity's organisational structure and any wider network with which the charity works	Para 1.51	
Relationship with any related parties	Para 1.51	
Other		

Reference and Administrative details

Charity name	Superficial Siderosis-The Silent Bleed
Other name the charity uses	N/A
Registered charity number	1169340
Charity's principal address	1 Laburnam Close, Aldershot GU113DX

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Jason Robert	CEO		
2	Sydney Fearn-Roberts	Trustee		
3				
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Reference and Administrative details

(cont)

Corporate trustees – names of the directors at the date the report was approved

Director name		
Jason Roberts		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

--

Exemptions from disclosure

Reason for non-disclosure of key personnel details

--

Other optional information

--

Declarations

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

Signed on behalf of the charity's trustees

Signature(s)

J Roberts

Full name(s)

Jason Roberts

Position (eg Secretary,
Chair, etc)

Founder

Date

15th April 2026

	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
Donations	286.66	119.8	137.74	318.1	459.44	184.44	328.8	163.9
Bank Deposit	0	0	0	0	0	415.3	0	0
Capital	0	0	0	0	0	0	10.23	0
Total Income	286.66	119.8	137.74	318.1	459.44	599.74	339.03	163.9
Insurance	25.76	25.76	25.76	0	0	25.76	25.76	25.76
Direct Debit	0	0	503.86	0	0	0	0	0
Website	4.99	4.99	4.99	4.99	4.99	4.99	4.99	4.99
Utilities	0	0	0	0	0	0	0	0
Telephone	0	0	0	0	0	0	0	0
Equipment	1.98	0.99	0	0	0	0	0	0
Sundries	0	0	0	0	0	0	3.5	163.28
Wages	817.5	1170	1785	0	1385	1170	3021.5	0
Total Expenditure	850.23	1201.74	2319.61	4.99	1389.99	1200.75	3055.75	194.03
Profit/Loss	-563.57	-1081.94	-2181.87	313.11	-930.55	-601.01	-2716.72	-30.13
Balance b/f	8052.49	7488.92	6406.98	4225.11	4538.22	3607.67	3006.66	289.94
profit/Loss	-563.57	-1081.94	-2181.87	313.11	-930.55	-601.01	-2716.72	-30.13
Balance c/f	7488.92	6406.98	4225.11	4538.22	3607.67	3006.66	289.94	259.81

June	July	Aug	Sept
751.73	1173.47	130.64	1297.14
0	0	0	0
0	0	0	0
751.73	1173.47	130.64	1297.14
25.76	25.76	25.76	25.76
108	0	0	0
4.99	4.99	4.99	4.99
0	0	0	0
0	0	0	0
0	0	0	0
0	19.38	3.09	0
1033.5	120	1430	693.75
1172.25	170.13	1463.84	724.5
-420.52	1003.34	-1333.2	572.64
259.81	-160.71	842.63	-490.57
-420.52	1003.34	-1333.2	572.64
-160.71	842.63	-490.57	82.07

SUPERFICIAL SIDEROSIS - THE SILENT BLEED

England & Wales - Charity number 1169340

Accounts

Trustees' annual report for the period



CHARITY COMMISSION
FOR ENGLAND AND WALES

Period start date Period end date

Charity name Charity No (if any)

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	For the public benefit, to advance the education of everyone about the rare condition Superficial Siderosis—specifically suffers of the condition, their carers, and their physicians.
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Additional information (optional)

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Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<p>Education & awareness: Website constantly updated with up-to-date Q&A advice from Dr Levy. Fundraising wristbands and information leaflets dispatched around the world.</p> <p>Research: we're excited and honoured to be part of a UK-based research project through Perspectum. .</p> <p>Support: Members supported in a closed social media group for carers and family as well as hundreds of individual private conversations with people affected by Superficial Siderosis</p>

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	SORP reference	
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Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	

Additional information (optional)

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Other		

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Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	By appointment

Additional information (optional)

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Other		

Reference and Administrative details

Charity name	Superficial Siderosis-The Silent Bleed
Other name the charity uses	N/A
Registered charity number	1169340
Charity's principal address	1 Laburnam Close, Aldershot GU113DX

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Jason Robert	CEO		
2	Amanda Fearn	Senior Officer		
3	Sydney Fearn-Roberts	Trustee		
4				
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Reference and Administrative details

(cont)

Corporate trustees – names of the directors at the date the report was approved

Director name		
Jason Roberts		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

--

Exemptions from disclosure

Reason for non-disclosure of key personnel details

--

Other optional information

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Declarations

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

Signed on behalf of the charity's trustees

Signature(s)

J Roberts

Full name(s)

Jason Roberts

Position (eg Secretary,
Chair, etc)

Founder

Date

22nd July 2025

	Oct	Nov	Dec	Jan	Feb	Mar	Apr
Donations	11.8	103.75	103.45	223.45	103.45	489.02	110.25
Bank Deposit	0	0	0	0	0	0	0
Capital	0	0	0	0	0	0	0
Total Income	11.8	103.75	103.45	223.45	103.45	489.02	110.25
Insurance	0	0	0	0	0	0	51.02
Direct Debit	0	0	0	359.99	0	0	0
Website	4.99	4.99	4.99	4.99	4.99	4.99	4.99
Utilities	0	0	0	0	0	0	0
Telephone	0	0	0	0	0	0	0
Equipment	79.99	0.99	0	0	0.99	0	0
Sundries	0	3.49	0	0	56.5	0	0
Wages	0	0	0	0	0	118.8	0
Total Expenditure	84.98	9.47	4.99	364.98	62.48	123.79	56.01
Profit/Loss	-73.18	94.28	98.46	-141.53	40.97	365.23	54.24
Balance b/f	7203.79	7130.61	7224.89	7323.35	7181.82	7222.79	7588.02
profit/Loss	-73.18	94.28	98.46	-141.53	40.97	365.23	54.24
Balance c/f	7130.61	7224.89	7323.35	7181.82	7222.79	7588.02	7642.26

May	June	July	Aug	Sept	Totals
508.19	551.79	2481.05	1049	50.66	
644.05	0	0	0	0	
0	0	0	0	0	
1152.24	551.79	2481.05	1049	50.66	6429.91
25.76	25.76	25.26	25.76	25.76	
0	0	0	0	0	
4.99	253.56	16.15	12.06	4.99	
0	0	0	0	0	
0	0	0	0	0	
1.98	0	85.44	0.99	0	
0	0	0	0	0	
0	353.72	1302.52	960	1749.81	
32.73	633.04	1429.37	998.81	1780.56	5581.21
1119.51	-81.25	1051.68	50.19	-1729.9	
7642.26	8761.77	8680.52	9732.2	9782.39	
1119.51	-81.25	1051.68	50.19	-1729.9	
8761.77	8680.52	9732.2	9782.39	8052.49	

SUPERFICIAL SIDEROSIS - THE SILENT BLEED

England & Wales - Charity number 1169340

Accounts

Trustees' annual report for the period



CHARITY COMMISSION
FOR ENGLAND AND WALES

Period start date Period end date

Charity name Charity No (if any)

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Reference and Administrative details

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Other name the charity uses	N/A
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Charity's principal address	1 Laburnam Close, Aldershot GU113DX

Names of the charity trustees who manage the charity

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3	Sydney Fearn-Roberts	Trustee		
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Reference and Administrative details

(cont)

Corporate trustees – names of the directors at the date the report was approved

Director name		
Jason Roberts		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

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Other optional information

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Declarations

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

Signed on behalf of the charity's trustees

Signature(s)

J Roberts

Full name(s)

Jason Roberts

Position (eg Secretary,
Chair, etc)

Founder

Date

22nd July 2025

	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
Donations	43.09	34.27	34.57	500.12	47.71	1323.51	216.77	76.43
Bank Depo:	0	0	0	0	0	0	0	0
Capital	0	0	0	0	0	0	0	0
Total Incon	43.09	34.27	34.57	500.12	47.71	1323.51	216.77	76.43
Insurance	0	0	0	0	0	0	0	0
Direct Debi	0	0	0	517.11	0	0	0	0
Website	4.99	458.59	0	4.99	4.99	4.99	4.99	4.99
Utilities	0	0	0	0	0	0	0	0
Telephone	0	0	0	0	0	0	0	0
Equipment	0	0	0	0	0	39.31	0	0.79
Sundries	0	0	0	0	0	0	0	0
Wages	0	0	0	0	0	0	0	0
Total Exper	4.99	458.59	0	522.1	4.99	44.3	4.99	5.78
Profit/Loss	38.1	-424.32	34.57	-21.98	42.72	1279.21	211.78	70.65
Balance b/l	5942.46	5980.56	5556.24	5590.81	5568.83	5611.55	6890.76	7102.54
profit/Loss	38.1	-424.32	34.57	-21.98	42.72	1279.21	211.78	70.65
Balance c/f	5980.56	5556.24	5590.81	5568.83	5611.55	6890.76	7102.54	7173.19

June	July	Aug	Sept	Totals
15.43	15.43	15.43	15.43	
0	0	0	0	
0	0	0	0	
15.43	15.43	15.43	15.43	2338.19
0	0	0	0	
0	0	0	0	
4.99	16.15	4.99	4.99	
0	0	0	0	
0	0	0	0	
0	0	0	0	
0	0	0	0	
0	0	0	0	
4.99	16.15	4.99	4.99	1076.86
10.44	-0.72	10.44	10.44	
7173.19	7183.63	7182.91	7193.35	
10.44	-0.72	10.44	10.44	
7183.63	7182.91	7193.35	7203.79	

SUPERFICIAL SIDEROSIS - THE SILENT BLEED

England & Wales - Charity number 1169340

Accounts



Trustees' Annual Report for the period						
From	Period start date			To	Period end date	
	30	09	2021		01	10
					2022	

Charity name	Superficial Siderosis - The Silent Bleed
Other names charity is known by	n/a
Registered charity number (if any)	1169340
Charity's principal address	1 Laburnam Close, Aldershot
	GU11 3DX

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Jason Roberts	CEO		
2	Amanda Fearn	Senior Officer		
3	Sydney Fearn-Roberts	Trustee		
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Foundation model constitution
How the charity is constituted (eg. trust, association, company)	CIO
Trustee selection methods (eg. appointed by, elected by)	By appointment

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

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Summary of the objects of the charity set out in its governing document

For the public benefit, to advance the education of everyone about the rare condition Superficial Siderosis – specifically suffers of the condition, their carers, and their physicians. To help fund ongoing, established and new medical and scientific research into Superficial Siderosis, by providing grants and establishing networks of professionals and patients through our website and social media.
To advance health and safe lives through information dissemination to Superficial Siderosis sufferers, carers and their physicians; in order to support sufferers in getting access to the medical care and treatments they

need. We will do this through our website, printed leaflets and other material and by organising social and virtual events using social media. The relief of those in need by reason of disability by providing advice and emotional support to sufferers, their carers and physicians. We will do this through our website, printed leaflets and other material and by organising social and virtual events using social media. The charity is for the benefit of Superficial Siderosis sufferers, their carers and their physicians worldwide, not just in the UK.

The trustees have reviewed the latest available guidance for trustees from the Charities Commission and have confirmed that they work within it. For example, when using money for printed materials, website running costs or buying consumables, the trustees have shown due prudence in making sure that we've obtained the best price, made efficiencies, not wasted materials and made sure they've considered value for money. They regularly refer back to the charitable objectives in the governing document, making sure that what they are doing is in line with the published aims. For example, the charity can offer a certain level of personal support and advice to individual people but stops short of legal advocacy and direct medical advice. Trustees understand that they need to be transparent, loyal and work for the interests of the charity.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Education: the charity continues to push for greater awareness by printing written materials, publishing articles and hosting a webinar on its website. It also links with other writers, researchers and bloggers concerned with Superficial Siderosis. A worldwide readership has access to the specialist, Dr Levy at Massachusetts General in the US through the charity's Q&A pages on the website. The charity also works with other organisations such as Superficial Siderosis Research Alliance, a research and fundraising group in Texas, US.

Research: the charity organises events throughout the year to raise money for research. It also serves as a base for others' fundraising efforts, providing support and charity-branded items.

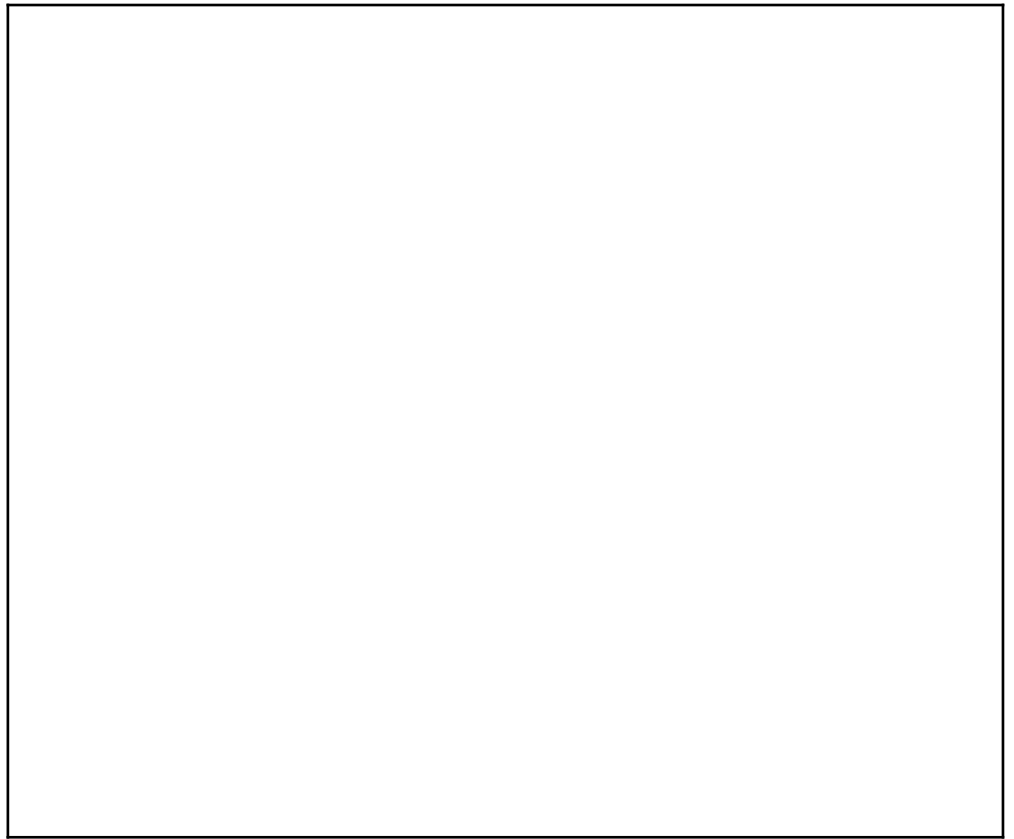
Support: a number of volunteers work with both those who have Superficial Siderosis and their carers and family. Via email, personal message, telephone and occasionally face-to-face, the charity helps people to come to terms with the illness, how to cope with work/study, how to get their doctor on board and guidance with where to turn to for treatment and specialist help.

Community: through social media and organising events, the charity has helped to build a strong, valid and enriched community of individuals. Superficial Siderosis is exceptionally rare and without the Silent Bleed, it is likely that this support network would not exist.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.



Summary of the main achievements of the charity during the year

Specifics:

Education & awareness: Website constantly updated with up-to-date Q&A advice from Dr Levy. Fundraising wristbands and information leaflets dispatched around the world.

Research: we're excited and honoured to be part of a UK-based research project through Perspectum. We were invited along to their patient focus group at the Royal Society in London on June 20/06/23. Organised by one of our members who has superficial siderosis and works for Perspectum. It was attended by several of our members from around the country. We're hoping to provide funds when they've completed their grant application.

Support: 191 members supported in a closed social media group for carers and family as well as hundreds of individual private conversations with people affected by Superficial Siderosis. 564 people supported in a group for patients with a similar number of private conversations, often on a 24/7 basis. A number of questions were fielded between members and Dr. Levy regarding complex and often personal issues regarding symptoms and medication.

Community: We're hoping that meets will go ahead this year.

Fundraising: Several planned for next year but none this year.

The future

The charity was established in September 2016.

This year, the charity wants to:

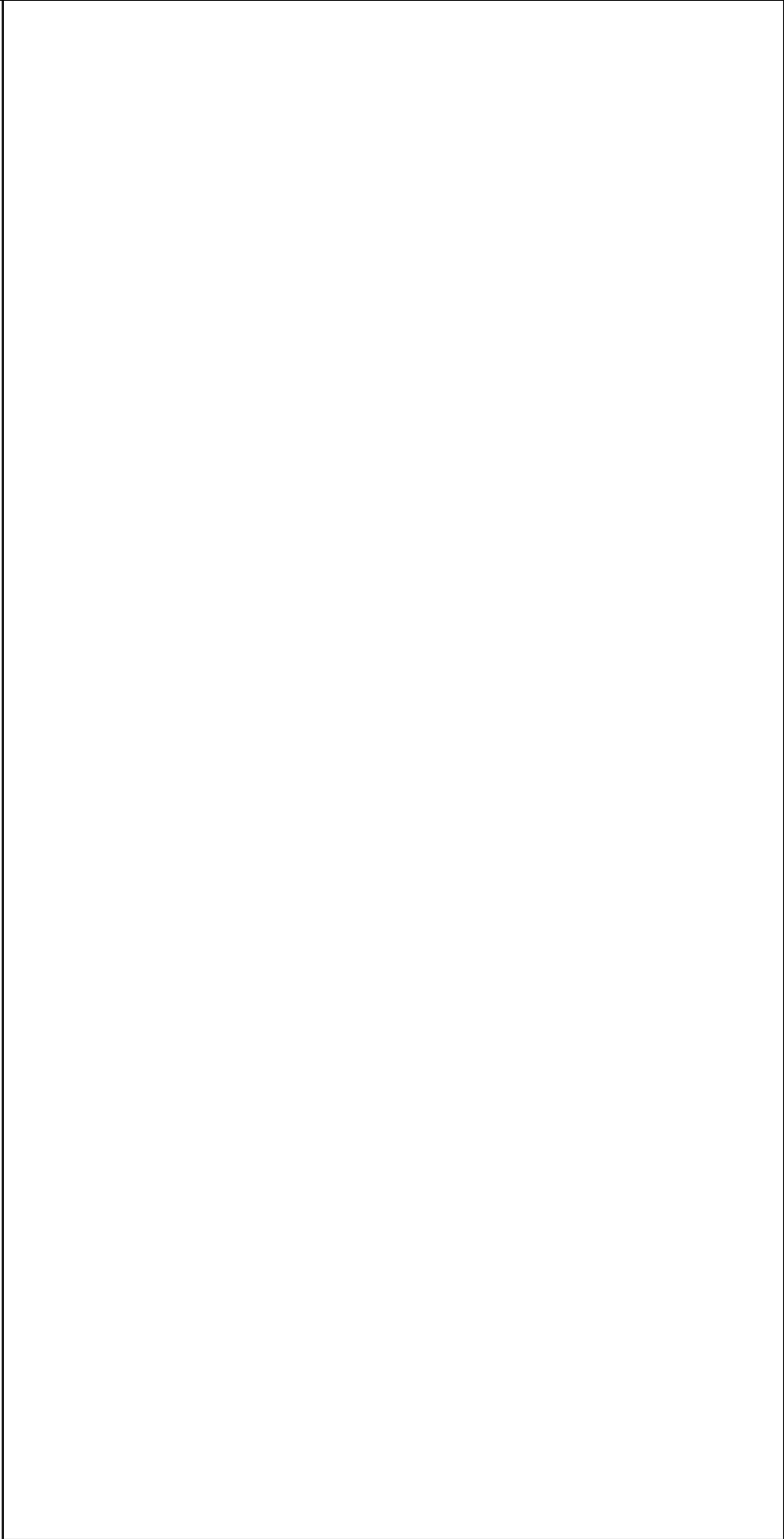
- Raise more money for research.
- Raise more awareness.
- Expand our use of social media to do the above.

But in order to do this, it needs to:

- Expand the team.
- Find funds for a paid team member to realise our social media goals – via charity funds or through a specific external grant.

We aim to achieve these points by working towards:

- Continuing to establish better links with other organisations and interested persons, so that the charity can share the work.
- Establishing better links with and joining in with the wider rare-disease community as a whole.
- Securing funding for a part-time member of staff to help with general, everyday handling of the charity, freeing up the trustees to manage and expand the charity's work.
- Building a network of fundraisers.
- Expanding the website and its connections and cooperation with other Superficial Siderosis and rare-disease organisations.



Brief statement of the charity's policy on reserves

The charity keeps a small amount in reserve every year. This is to cover modest, regular running costs such as printing leaflets and paying for website hosting. We have funds earmarked for a UK-based research project, we're just waiting until it gets underway to start the grant-making process.

Details of any funds materially in deficit

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Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The charity is, at the moment, funded by fundraisers and individual gifts, largely through the website (some regular, some one-off). The charity has plans to explore other avenues such as applying to other charities and trusts for assistance.

Spending has supported the aims of the charity by allowing it to print leaflets, keep the website running, and provide resources and publicity for fundraising. The charity also makes grants to specific specialist doctors/institutions to assist ground-breaking research into Superficial Siderosis.

Section F Other optional information

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

Signed on behalf of the charity's trustees

Signature(s) J Roberts	A Fearn
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Full name(s) Jason Roberts	Amanda Fearn
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Position (eg Secretary, Chair, etc) Founder	Senior Officer
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Date 30/07/23

Silent Bleed accounts 01/10/21 to 30/09/22					
Charity number 1169340					
Income and outgoings			In	Out	Balance
Grand totals			£1,857.62	-341.98	£1,515.64
Money in			In		
Date					
14/10/21	£20.00	CAF donation	£20.00		
14/10/21	£432.24	Bank Deposit	£432.24		
20/10/21	£38.82	Enthuse	£38.82		
01/11/21	£30.81	Post Office Deposit	£30.81		
16/11/21	£20.00	CAF donation	£20.00		
19/11/21	£78.00	Enthuse	£78.00		
15/12/21	£160.77	Bank Deposit	£160.77		
16/12/21	£20.00	CAF donation	£20.00		
21/12/21	£19.02	Enthuse	£19.02		
22/12/21	£30.81	Post Office Deposit	£30.81		
31/12/21	-£359.99	Enthuse	-£359.99		
11/01/22	£20.00	Bank Deposit	£20.00		
14/01/22	£20.00	CAF donation	£20.00		
19/01/22	£271.52	Enthuse	£271.52		
16/02/22	£20.00	CAF donation	£20.00		
21/02/22	£294.37	Enthuse	£294.37		
01/03/22	£30.81	Bank Deposit	£30.81		
16/03/22	£20.00	CAF donation	£20.00		
17/03/22	£33.31	Charities Trust	£33.31		
21/03/22	£19.02	Enthuse	£19.02		
14/04/22	£33.31	Charities Trust	£33.31		
20/04/22	£69.02	Enthuse	£69.02		
20/04/22	£31.81	Post Office Deposit	£31.81		
16/05/22	£20.00	CAF donation	£20.00		
19/05/22	£19.02	Enthuse	£19.02		
31/05/22	£33.31	Charities Trust	£33.31		
16/06/22	£20.00	CAF donation	£20.00		
21/06/22	19.02	Enthuse	19.02		
14/07/22	£20.00	CAF donation	£20.00		
19/07/22	£19.02	Enthuse	£19.02		
29/07/22	£38.76	Charities Trust	£38.76		
16/08/22	£20.00	CAF donation	£20.00		
17/08/22	£4.07	Charities Trust	£4.07		
22/08/22	£19.02	Enthuse	£19.02		
02/09/22	£128.66	Bank Deposit	£128.66		
15/09/22	£20.00	CAF donation	£20.00		
16/09/22	£4.07	Charities Trust	£4.07		
21/09/22	£119.02	Enthuse	£119.02		
Silent Bleed accounts 01/10/21 to 30/09/22					
Charity number 1169340					

					Grand total			
Totals					-341.98			
Date	Website	Stationery	Equipment	Sundries				
01/10/21				-£13.00	-£13.00	Home as office		
11/10/21		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
01/11/21				-£13.00	-£13.00	Home as office		
11/11/21		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
01/12/21				-£13.00	-£13.00	Home as office		
11/12/21		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
01/01/22				-£13.00	-£13.00	Home as office		
11/01/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
01/02/22				-£13.00	-£13.00	Home as office		
11/02/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
01/03/22				-£13.00	-£13.00	Home as office		
11/03/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
27/03/22				-£2.33	-£2.33	USB connector		
01/04/22				-£13.00	-£13.00	Home as office		
08/04/22				£0.00	£0.00	USB connector		
11/04/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
01/05/22				-£13.00	-£13.00	Home as office		
01/06/22				-£13.00	-£13.00	Home as office		
10/06/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
11/06/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
22/06/22				-£77.00	-£77.00	Charity pots - Ebay		
01/07/22	-£11.16				-£11.16	Domain		
01/07/22				-£13.00	-£13.00	Home as office		
11/07/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
19/07/22				-£7.69	-£7.69	Reading glasses - Ebay		
01/08/22				-£13.00	-£13.00	Home as office		
11/08/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
01/09/22				-£13.00	-£13.00	home as office		
11/09/22				-£22.95	-£22.95	Fan		
11/09/22				-£4.97	-£4.97	Reading glasses - Ebay		
11/09/22		-£4.99			-£4.99	Site Search-Fast Simon-Starter		
					£0.00			
					£0.00			

SUPERFICIAL SIDEROSIS - THE SILENT BLEED

England & Wales - Charity number 1169340

Accounts



Trustees' Annual Report for the period

From: 01/10/20 **Period start date** **To:** 30/09/21 **Period end date**

Charity name: The Silent Bleed

Charity registration number: 1169340

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	<p>For the public benefit, to advance education of everyone about the rare disease Superficial Siderosis – specifically suffers of the disease, their carers, and their physicians. To help fund ongoing, established and new medical and scientific research into Superficial Siderosis, by providing grants and establishing networks of professionals and patients through our website and social media.</p> <p>To advance health and safe lives through: information dissemination to Superficial Siderosis suffers, carers and their physicians; in order to support suffers in getting access to the medical care and treatments they need. We will do this through our website, printed leaflets and other material and by organising social and virtual events using social media.</p> <p>The relief of those in need by reason of disability by providing advice and emotional support to sufferers, their carers and physicians. We will do this through our website, printed leaflets and other material and by organising social and virtual events using social media.</p> <p>The charity is for the benefit of Superficial Siderosis sufferers, their carers and their physicians worldwide, not just in the UK.</p>
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	<p>Education: the charity continues to push for greater awareness by printing written materials and publishing articles and hosting a webinar on its website. It also links with other writers, researchers and bloggers concerned with Superficial Siderosis. A worldwide readership has access to the specialist, Dr Levy at Massachusetts General in the US through the charity's Q&A pages on the website. The charity also works with other organisations such as Superficial Siderosis Research Alliance, a</p>

		<p>research and fundraising group in Texas, US.</p> <p>Research: the charity organises events throughout the year to raise money for research. It also serves as a base for others' fundraising efforts, providing support and charity branded paraphernalia.</p> <p>Support: a number of volunteers work with both those who have Superficial Siderosis and their carers and family. Via email, personal message, telephone and occasionally face-to-face, the charity helps people to come to terms with the illness, how to cope with work/study, how to get their doctor on board and guidance with where to turn to for treatment and specialist help.</p> <p>Community: through social media and organising events, the charity has helped to build a strong, valid and enriched community of individuals. Superficial Siderosis is exceptionally rare and without the Silent Bleed, it is likely that this support network would not exist.</p> <p>Note: Our usual face-to-face activity has been hampered this year due to Covid-19 restrictions. As things open up, we should be able to resume.</p>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees have reviewed the latest available guidance for trustees from the Charities Commission and have confirmed that they work within it.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	
Policy on social investment including program related investment	Para 1.38	
Contribution made by volunteers	Para 1.38	
Other		

Achievements and Performance

	SORP reference	
<p>Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.</p>	<p>Para 1.20</p>	<p>Specifics:</p> <p>Education & awareness: Website constantly updated with up-to-date Q&A advice from Dr Levy. Fundraising wristbands and information leaflets dispatched around the world.</p> <p>Research: Funds given to Dr Levy's research programme into Superficial Siderosis.</p> <p>The leaflet is available to download for free on the website and it is updated regularly.</p> <p>Support: 165 members supported in a closed social media group for carers and family as well as hundreds of individual private conversations with people affected by Superficial Siderosis. 503 people supported in a group for patients with a similar number of private conversations, often on a 24/7 basis. A number of questions fielded between members and Dr Levy at Massachusetts General regarding complex and often personal issues regarding symptoms and medication.</p> <p>Community: No meets this year due to Covid 19</p> <p>The future</p> <p>The charity was established in September 2016.</p> <p>This year, the charity wants to:</p> <ul style="list-style-type: none"> • Raise more money for research. • Raise more awareness. • Expand our use of social media to do the above. <p>We aim to achieve these points by working towards:</p> <ul style="list-style-type: none"> • Continuing to establish better links with other organisations and interested persons, so that the charity can share the work. • Establishing better links with and joining in with the wider rare-disease community as a whole. • Securing funding for a part-time member of staff to help with general, everyday handling of the charity, freeing up the trustees to manage and expand the charity's work. • Building a network of fundraisers.

		<ul style="list-style-type: none"> Expanding the website and its connections and cooperation with other Superficial Siderosis and rare-disease organisations.
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Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	
Performance of fundraising activities against objectives set	Para 1.41	
Investment performance against objectives	Para 1.41	
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	The charity account is in credit
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The charity keeps a small amount in reserve every year. This is to cover modest, regular running costs such as printing leaflets and paying for the website hosting.
Amount of reserves held	Para 1.22	
Reasons for holding zero reserves	Para 1.22	n/a
Details of fund materially in deficit	Para 1.24	n/a
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	n/a

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	
Investment policy and objectives including any social investment policy adopted	Para 1.46	
A description of the principal risks facing the charity	Para 1.46	
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	Foundation model constitution
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Every trustee must be appointed by a resolution passed at a properly convened meeting of the charity trustees.

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	
The charity's organisational structure and any wider network with which the charity works	Para 1.51	
Relationship with any related parties	Para 1.51	
Other		

Reference and Administrative details

Charity name	The Silent Bleed
Other name the charity uses	n/a
Registered charity number	1169340
Charity's principal address	1 Laburnam Close, Aldershot, GU11 3DX

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Jason Roberts	Founder		
2	Amanda Fearn	Senior Officer		
3	Sydney Fearn-Roberts	Trustee		
4				
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17				
18				
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20				

Corporate trustees – names of the directors at the date the report was approved

Director name		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	None
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

None

Other optional information

None

Declarations

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

Signed on behalf of the charity's trustees

Signature(s)	J Roberts	<i>A Fearn</i>
Full name(s)	Jason Roberts	Amanda Fearn
Position (eg Secretary, Chair, etc)	CEO	Senior officer
Date	28/07/22	

Silent Bleed accounts 01/10/20 to 30/09/21						
Charity number 1169340						
Income and outgoings paid to Jason on cheque 100028						
Totals	-£766.86	£0.00	-£354.99	-£53.13	Grand total	-£1,174.98
Date	Website	Stationery	Equipment	Sundries		
11/07/2020	-£4.99				-£4.99	Wix search
11/08/2020	-£4.99				-£4.99	Wix search
11/09/2020	-£4.99				-£4.99	Wix search
11/10/2020	-£4.99				-£4.99	Wix search
04/11/2020				-£4.20	-£4.20	Post
05/11/2020				-£45.93	-£45.93	Underpayment of cheque 26
11/11/2020	-£4.99				-£4.99	Wix search
05/12/2020	-£226.80				-£226.80	Vimeo
11/12/2020	-£4.99				-£4.99	Wix search
31/12/2020	-£359.99				-£359.99	DD to Go Cardless
11/01/2021	-£4.99				-£4.99	Wix search
14/02/2021	-£4.99				-£4.99	Wix search
01/03/2021			-£164.99		-£164.99	Printer
14/03/2021	-£4.99				-£4.99	Wix search
11/04/2021	-£4.99				-£4.99	Wix search
04/05/2021	-£115.20				-£115.20	Wix premium plan
14/05/2021	-£4.99				-£4.99	Wix search
15/05/2021				-£3.00	-£3.00	Copier paper
24/05/2021			-£190.00		-£190.00	Keith Moran computer repair
11/09/2021	-£4.99				-£4.99	Wix search
11/10/2021	-£4.99				-£4.99	Wix search