



Trustees' Annual Report for the period

From

Period start date

30

09

2021

To

Period end date

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

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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

<p>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.</p> <p>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</p>
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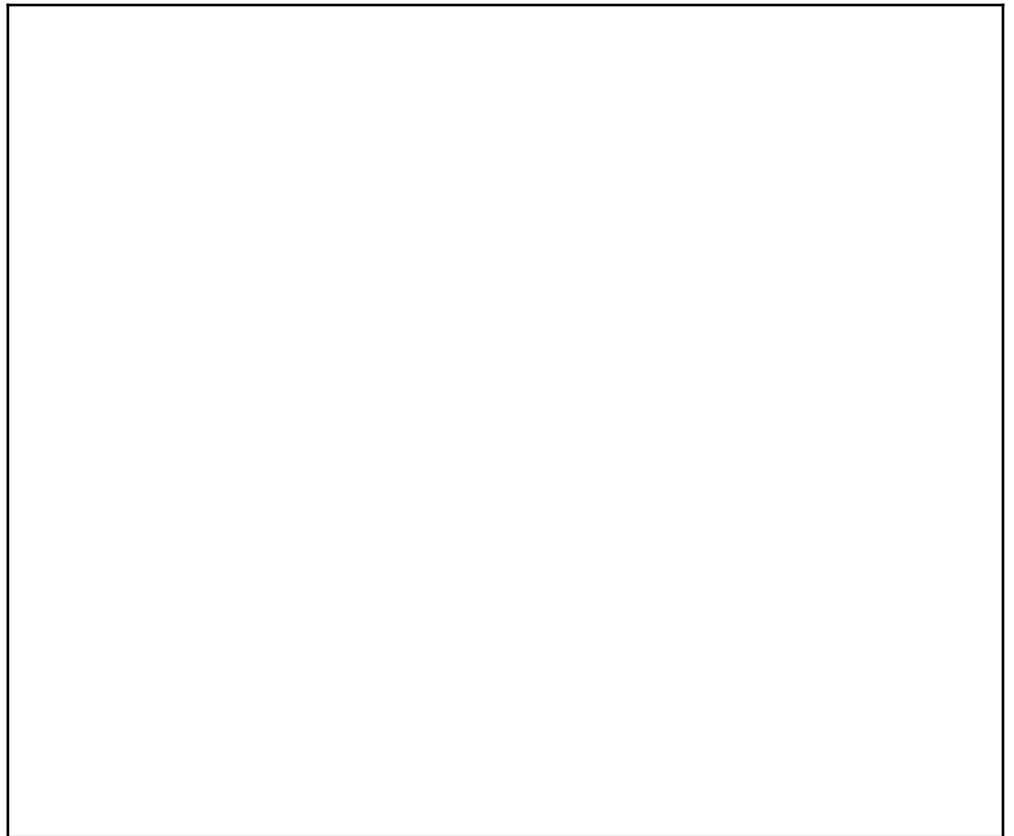
	<p>need. We will do this through our website, printed leaflets and other material and by organising social and virtual events using social media. The relief of those in need by reason of disability by providing advice and emotional support to sufferers, their carers and physicians. We will do this through 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.</p> <p>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.</p> <p>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.</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 items.</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>
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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)

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:

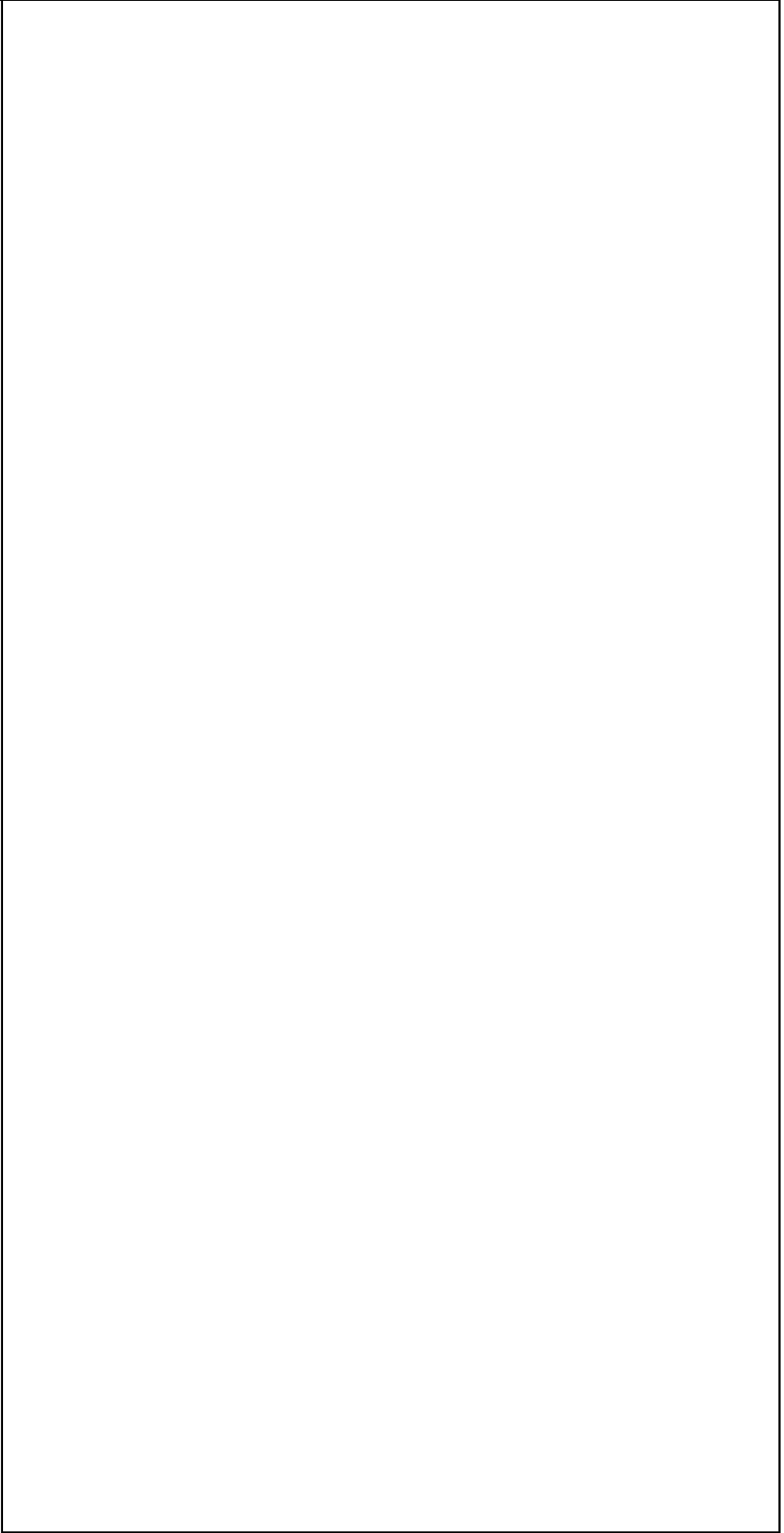
- Raise more money for research.
- Raise more awareness.
- Expand our use of social media to do the above.

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

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

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

Full name(s) Jason Roberts

Amanda Fearn

Position (eg Secretary, Chair, etc) Founder

Senior Officer

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		Detail			
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					