



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

[illegible]

Name of trustees holding title to property belonging to the charity

[illegible]

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

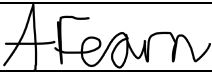
Other optional information

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	
Full name(s)	Jason Roberts	Amanda Fearn
Position (eg Secretary, Chair, etc)	CEO	Senior officer
Date	28/07/22	

[illegible]

[illegible]

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		