



Trustees' Annual Report for the period

Period start date
From 01.01.2024

Period end date
To 31.12.2024

Charity name: Sturge Weber UK

Charity registration number: 1016688

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	Sturge Weber UK inspires to promote research and share knowledge to empower individuals diagnosed with Sturge Weber Syndrome and their families and carers. Giving strength to create a supportive, inclusive and caring community whilst raising both public and professional awareness
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	<ul style="list-style-type: none">- To provide strength and support for individuals diagnosed with Sturge Weber Syndrome and their families and carers.- To promote awareness of the syndrome and to raise both public and professional awareness of the condition.- To promote medical research into the causes and treatment of this syndrome.- To offer to connect individuals diagnosed with Sturge Weber Syndrome and their families to create a supportive community via social media and face to face events and offer a Family Weekend annually for families across the UK and Ireland.- To provide a quarterly newsletter for members- To work with health professionals to have a greater understanding and create a collaborative approach in the level of care from providing a diagnosis to treatment plan and wellbeing for a person with Sturge Weber Syndrome throughout their life.- To empower our families by keeping up to date with changes in legislation, services and signposting to relevant external agencies for a co-productive approach to supporting them in meeting their best outcomes Overall, Sturge Weber UK plays a crucial role in supporting individuals and families affected by Sturge Weber syndrome in the UK, as well as raising awareness and promoting research to improve the quality of life for those living with this rare condition.
Statement confirming whether the trustees have	Para 1.18	A comprehensive list of statutory and non-statutory policies are in place. Please see our website for

had regard to the guidance issued by the Charity Commission on public benefit		statutory policies, other policies are available on request
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Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	A comprehensive list of statutory and non-statutory policies are in place. Please see our website for statutory policies, other policies are available on request
Policy on social investment including program related investment	Para 1.38	Not applicable
Contribution made by volunteers	Para 1.38	A comprehensive list of statutory and non-statutory policies are in place. Please see our website for statutory policies, other policies are available on request
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>This year has been a remarkable one for Sturge Weber UK, marked by progress, impactful events, and strong community engagement.</p> <p>In January 2024, the trustees participated in an invaluable face-to-face training session, supported by Nicola Colenso. During this session, we revisited essential questions: who are we as a charity, what do we do, and who do we support. This work served to refocus and reenergise the Trustees, ensuring clarity in our mission and purpose.</p> <p>Our ongoing auditing process continued, demonstrating our commitment to transparency and accountability.</p> <p>Active in April proved to be a tremendous success, raising an impressive £3,401.67, thanks to the collective effort and enthusiasm of our members and supporters.</p> <p>The Family Weekend was another highlight of the year, bringing together members of our community for a memorable event. We were privileged to host enlightening talks by SIBs and Contact, and the inclusion of members with a diagnosis of Sturge</p>

		<p>Weber Syndrome made the event even more meaningful. A meeting held prior to the AGM allowed us to discuss the AGM pack with members, ensuring open communication and participation.</p> <p>During the AGM, we were pleased to welcome Mike Grimes as Secretary, marking a positive step for our team’s growth and governance.</p> <p>Fundraising in 2024 reached remarkable heights, and we are deeply grateful to our dedicated supporters. During 2024, the funds received from the shop, various fundraising activities, family weekend sales, raffles, and bank interest amounted to £43,529.60. Expenses for the year, including overheads, family weekend costs, shop stock, and meetings, totalled £43,154.07, resulting in a profit of £375.53. This means that no reserves were required to run the charity in 2024—a testament to the incredible dedication and hard work of our fundraisers.</p> <p>We would like to extend heartfelt thanks to the following individuals and groups for their exceptional contributions: Marc Divers, Adam Leake, Becky Blount, Bella Parsons, Melissa Brandon, Emily Summerson, Peter Stele, East Riding Rangers U14s, Ashton Bears, Theo Stimpson, Jade McCormick, Natasha Reidie, Burns School of Black Belts, Linda Adams, Fred Sutton, all members that took part in Active in April, and donations made in memory of Betty McLeod.</p> <p>Additionally, we provided grants totalling £1,309.73 to our members, furthering our commitment to supporting the Sturge Weber community.</p> <p>We are proud to announce several strategic advancements made this year. We have now developed a comprehensive fundraising strategy, launched the Stronger Together campaign, formulated a growth plan, and established a streamlined fundraising workflow. Additionally, we have applied for grants and successfully developed a members-only access section on our website, enhancing our online resources and engagement.</p> <p>Following the training earlier in the year, we have also identified key roles that need to be filled to strengthen our governance and operations further. These roles include Secretary, Fundraising Trustee, Engagement Trustee, Marketing Trustee, and Compliance Trustee.</p> <p>As we look back on 2024, it is clear that it was a year of growth, collaboration, and success. Thank you to everyone who played a role in making this possible. Together, we continue to make a difference.</p>
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Additional information (optional)

You may choose to include further statements where relevant about:

	<p>Para 1.41</p>	
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Achievements against objectives set		Make a difference grants have supported families and members with a diagnosis of Sturge Weber Syndrome. Family Weekend whilst being the biggest expense to the charity gives invaluable support to members.
Performance of fundraising activities against objectives set	Para 1.41	Funds raised are used for the Family Weekend and Grants for members
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	<p>In 2024 we saw an increase in activity and engagement with the charity once again. Sturge Weber UK continued to show a financially good position as of 31st December 2024, with the bank balance at £89,100. Receipts in 2024 were £43,500. Payments from the account were £43,154. Our commitment to arranging an annual Family Weekend is our largest expense as is our Make a Difference Grant Scheme which we believe are valuable contribution to the charity's aims.</p> <p>The charity is run by volunteers, there are no paid staff. Travel and subsistence costs for trustee meetings are reimbursed. We are extremely grateful to every fundraiser for their efforts, large or small.</p> <p>Detail Receipts via fundraising events we received in £26,622 and donations were £2,733 in 2024. We received £523 from the government in gift aid.</p> <p>The family weekend raised £11,092 from the payments received from members contributions towards the cost of the weekend and the raffle and auction. We also received in £811 in interest from the bank.</p>
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		<p>The online shop and shop at the Family Weekend in 2023 raised £1,748 and helped to spread awareness too.</p> <p>Payments in 2024 amounted to £43,154. The Family Weekend cost £33,886 to run. The next largest outgoing in 2024 was £2,658 for operational costs including postage, printing, insurance and memberships.</p> <p>Shop purchases were £948</p> <p>Fees for accountancy and online platforms were £2426</p> <p>Spending on meetings was £1788. Finally, to remain compliant we refreshed some of our training and trained new trustees, spending £352.</p> <p>Sturge Weber UK is a small charity not subject to statutory audit and the accounts are compiled on a cash basis. For this reason, there are no adjustments in the accounts for shop stock, pre-payments and accruals.</p>
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	<p>The charity aims to hold funds in reserve for the reason detailed below:-</p> <ul style="list-style-type: none"> • Projects suggested by charity members • Aid research into Sturge Weber Syndrome • Raising awareness of SWS amongst professionals, families and public • For people with SWS who are in need • Ongoing support • One off projects and support
Amount of reserves held	Para 1.22	At the year-end the charity held £88,457 of cash reserves, of which £15,000 were restricted and £73,457 unrestricted. It is our policy to hold a minimum of £55,000 in unrestricted reserves.
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	Lack of fundraising Unsuccessful grant applications

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	Fundraising by members, Active in April Campaign Grants
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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	None engagement of members, unsuccessful grant applications, lack of fundraising
Other		

Structure, Governance and Management

Description of charity's trusts:		Board of Trustees
Type of governing document (trust deed , royal charter)	Para 1.25	Constitution
How is the charity constituted? (e.g unincorporated association , CIO)	Para 1.25	Charity
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	Appointed by the Trustee Team and elected by the charity members.

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	All trustees and volunteers undergo induction and training as per our policies and procedures.
The charity's organisational structure and any wider network with which the charity works	Para 1.51	There are 5 trustees and 4 volunteers in 2024.
Relationship with any related parties	Para 1.51	Sturge Weber UK has productive working relationships with the SWaNs clinic at Great Ormond Street and Dr Eriksson at UCLH.
Other		The Trustees conduct comprehensive risk assessments where needed.

Reference and Administrative details

Charity name	Sturge Weber UK
Other name the charity uses	SW UK
Registered charity number	1016688
Charity's principal address	Milk Hall Withens Lane Barkisland HX4 0DY

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	Marie Cavalier	Chair		Trustee committee/charity members
2	Carolyn Burns	Treasurer		Trustee committee/charity members
3	Claire Trevor	Engagement		Trustee committee/charity members
4	Steve Waters	Digital and IT		Trustee committee/charity members
5	Mike Grimes	Secretary	May 2024	Trustee committee/charity members
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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	N/A
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

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)	<i>Marie Cavalier</i>	
Full name(s)	Marie Cavalier	
Position (eg Secretary, Chair, etc)	Chair	
Date	27 th March 2025	



Receipts and payments accounts

For the period from	Period start date 01-Jan-24	To	Period end date 31-Dec-24
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	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Bank Interest	811	-	-	811	588
Gift Aid	523	-	-	523	3,896
Donations	2,733	-	-	2,733	1,875
Family Weekend	11,092	-	-	11,092	6,438
Fundraising	26,622	-	-	26,622	28,410
Shop	1,748	-	-	1,748	1,895
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	43,530	-	-	43,530	43,103
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	43,530	-	-	43,530	43,103
A3 Payments					
Accountancy Fees	1,170	-	-	1,170	1,116
Awareness	-	-	-	-	84
Communication	-	-	-	-	178
Equipment	1,913	-	-	1,913	2,292
Family Weekend	33,886	-	-	33,886	37,616
Fees	1,256	-	-	1,256	939
Gifts	215	-	-	215	100
Grant	1,310	-	-	1,310	-
Insurance	180	-	-	180	163
Memberships	60	-	-	60	173
Postage	75	-	-	75	307
Printing & Stationery	-	-	-	-	101
Projects	-	-	-	-	5,270
Purchases	948	-	-	948	960
Sundry	-	-	-	-	8
Training	352	-	-	352	948
Trustee Meetings	1,788	-	-	1,788	955
	-	-	-	-	-
Sub total	43,153	-	-	43,153	51,209
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	43,153	-	-	43,153	51,209
Net of receipts/(payments)	377	-	-	377	- 8,106
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	73,457	15,000	-	88,457	-
Cash funds this year end	73,834	15,000	-	88,834	- 8,106

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Current Bank Account	20,869	-	-
	Deposit Bank Account	53,232	15,000	-
	Credit card	- 267	-	-
	Total cash funds	73,834	15,000	-

(agree balances with receipts and payments account(s))

OK OK OK



Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Credit card		267	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Marie Cavalier	2025-04-09
	Carolyn Burns	2025-04-09



Section A Independent Examiner's Report

Report to the trustees	Sturge Weber UK		
On accounts for the year ended	31 December 2024	Charity no (if any)	1016688
Set out on pages	1 to 12		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 December 2024.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:		Date:	2025-04-09
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Name: Jonathan Stead

Relevant professional qualification(s) or body (if any): FCCA

Address: Sleigh & Story Ltd
Thornhill Brigg Mills, Thornhill Beck Lane, Brighouse. HD6 4AH.

Document electronically signed



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