



Trustees' Annual Report for the period

Period start date
From 01.01.2023

Period end date
To 31.12.2023

Charity name: Sturge Weber UK

Charity registration number: 202++99

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>After the success and momentum of 2022, I am pleased to say that this continued into 2023. Auditing the Charity continues as does the review of our policies annually. The purpose of this is to keep the Trustees working towards the aims of the members and the charity goals. Further training has been undertaken by the Trustees to keep them compliant and upskill them.</p> <p>In January the Trustees had a face-to-face meeting at the Hilton Coventry to arrange the family weekend and undertake in training with our mentor Nicola Colenso. The result of this training was that we were able to reflect on the SWOT analysis we undertook 2 years earlier and establish which tasks we had completed, and which tasks remained uncompleted. The result of this was that highlighted the need for new Trustee roles within the charity and gave us an opportunity to write the job descriptions for the roles we had established need filling. On return from the</p>

		<p>training the roles of Digital/IT Trustee and Engagement Trustee were advertised.</p> <p>Active in April was another success this year. The annual event is a chance for our members and supporters to not only raise money for our charity but also raise awareness of Sturge Weber syndrome in your local community. The amount raised was £1767.</p> <p>After advertising the new Trustee roles we were pleased to conduct interviews for the roles and successfully appoint two new trustees.</p> <p>We were pleased to see more families choosing to join us for the Family Weekend and even happier to see that this was enjoyed by all that were in attendance. The weekend again took a more laid-back approach. The weekend began on the Friday evening where members were invited to eat in the restaurant with their family and settle into the hotel before the start of the formal side of the weekend on the Saturday. On Saturday, the weekend started with a meet the Trustees and an interactive session of what the Trustees and charity have been doing in the last 3 years and collaboration with the members as to what you want the charity aims and mission to be.</p> <p>On Sunday the AGM was held and Claire was voted in as engagement Trustee and Steve as Digital/IT Trustee. The AGM was sent to all members via email 2 weeks before to allow members to read the documentation and raise questions prior to the AGM. A presentation was then given via Zoom by Rion Walsh discussing difficult behaviours and management of ASD and ADHD. After lunch on Sunday was free time where some families chose to go on a whole family trip to Coombes Abbey Park and others chose to stay in the hotel and make use of the Activity club, hotel facilities and just have time to socialise with others.</p> <p>The raffle was fantastic and ran over the course of Saturday and Sunday due to the generosity of members and supporters.</p> <p>The feedback from the Family Weekend was that our members would like the Charity to hold this annually. As a result of this feedback the next Family Weekend will be held at The Doubletree Hilton in Coventry on Friday 24th May to Monday 27th May 2024.</p>
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		<p>As a result of the interactive session at the Family Weekend we have successfully launched the Charity new tag line of Strength Awareness Support. The charity mission statement has also been updated to:</p> <p>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.</p> <p>Fundraising in 2023 was increased which is incredible to see. Whilst payments out were increased because of the Family Weekend the receipts in the bank were £43,103 which after the payments out meant that the deficit to the Charity funds was only £8,801. I hope that the increased fundraising continues as this allows the Family Weekend to run annually and allows grant applications to be given to members.</p> <p>As a result of a few beers and a few dads bonding over the family weekend the Dad's Walking Challenge was agreed. 4 dads agreed to take part in October in a challenge to take on the Welsh 3000's. As we are sure you appreciate this was not for the faint hearted. Many hours were put into this challenge in preparation, planning and engagement to get much needed kit in support to the challenge. It was certainly not a challenge you could turn up on the weekend and have a go. The challenge alone raised £12490.</p> <p>Thank you all our supporters in 2023 and for the many events run on our behalf and money donated in memory of and other donations.</p> <p>The whole team had the pleasure of joining the team at Great Ormond Street Hospital for an Away Day. The Away Day was a fantastic opportunity for us to work with the team at GOSH to discuss our feedback of them and their proposals, support them in areas we feel that the members have discussed that need improving and an opportunity them to feedback to us how they feel we can support our members better. As a result of this away day the Trustees are working with the Swanns team on various projects to help with transition to nursery, school, college and further support and signpost families.</p>
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		<p>The Make a Difference Grant scheme was again successful in 2023. We are pleased to attach a report of the grants that have been granted in since the start of the grant scheme. As you can see from the attached list, we were able to release 10 grants to members in 2023. I hope that by attaching the grants that have been released under the Make a Difference Grant Scheme it will show you the things we have been able to release money to members for. The Make a Difference Grant scheme closed as the end of December as this is being relaunched in 2024.</p> <p>We have welcomed a new volunteer to our Friends of Sturge Weber UK team. Kerrie Hiscock joined with a view to working alongside the Trustees for 6 months and then deciding whether a Trustee role is something she would like to take up.</p> <p>The Cuppa and Catch Ups have continued and are an opportunity for us to catch up over Zoom and chat. They have been well received by members.</p> <p>Monthly updates are now quarterly updates and continue to be well received by members.</p> <p>The charity has moved forward considerably again in 2023 and I would like to thank the trustees and volunteers for their support, time, and dedication. I would also like to thank the fundraisers and members for their continued support. The main priority for 2024 is again to work on member engagement and growing the Trustee team to strengthen the Charity. Thank you for your support.</p>
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Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	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 2023 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 2023, with the bank balance at £88,457. Receipts in 2023 were £42,408. Payments from the account were £51,209. 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>
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	£55,000
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	<p>Lack of fundraising Unsuccessful grant applications</p>

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	<p>Fundraising by members, Active in April Campaign Grants</p>

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 4 trustees and 4 volunteers in 2023.
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	Acting Treasurer		Trustee committee/charity members
3	Claire Trevor	Acting Secretary		Trustee committee/charity members
4	Steve Waters	Digital and IT		Trustee committee/charity members
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17				
18				
19				
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	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
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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	19 th April 2024	



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
Sturge Weber UK

No. (if any)
1016689

Receipts and payments accounts

CC16a

For the period from	Period start date	To	Period end date
	01-Jan-23		31-Dec-23

	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	588	-	-	588	277
Gift Aid	3,896	-	-	3,896	2,049
Donations	1,875	-	-	1,875	7,011
Family Weekend	6,438	-	-	6,438	5,680
Fundraising	28,410	-	-	28,410	13,223
Shop	1,895	-	-	1,895	2,054
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	43,103	-	-	43,103	30,294
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	43,103	-	-	43,103	30,294
A3 Payments					
Accountancy Fees	1,116	-	-	1,116	696
Awareness	84	-	-	84	541
Communications	178	-	-	178	201
Equipment	2,292	-	-	2,292	179
Family Weekend	37,616	-	-	37,616	24,203
Fees	939	-	-	939	890
Gifts	100	-	-	100	38
Insurance	163	-	-	163	217
Memberships	173	-	-	173	85
Postage	307	-	-	307	539
Printing & Stationery	101	-	-	101	485
Projects	5,270	-	-	5,270	5,825
Purchases	960	-	-	960	3,924
Sundry	8	-	-	8	-
Training	948	-	-	948	236
Trustee Meetings	955	-	-	955	298
	-	-	-	-	-
Sub total	51,209	-	-	51,209	38,357
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	51,209	-	-	51,209	38,357
Net of receipts/(payments)	- 8,106	-	-	- 8,106	- 8,063
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	81,563	15,000	-	96,563	-
Cash funds this year end	73,457	15,000	-	88,457	- 8,063

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Current Bank Account	21,028	-	-
	Deposit Bank Account	52,429	15,000	-
		-	-	-
	Total cash funds	73,457	15,000	-

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

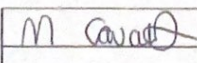
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	MARIE CAVALIER	19.11.24



Section A

Independent Examiner's Report

Report to the trustees

Charity Name

STURGE WEBER UK

On accounts for the year
ended

31 DECEMBER 2023

Charity no
(if any)

1016688

Set out on pages

3 - 15

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30 / 12 / 2023.

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

~~[The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of [insert name of applicable listed body]]. Delete [] if not applicable.~~

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination (other than that disclosed below *) 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.

* Please delete the words in the brackets if they do not apply.

Signed:

Date:

1 JULY 2024

Name:

JONATHAN STEAD

Relevant professional
qualification(s) or body

FCCA

(if any): SLEIGH & STORY LTD

Address: THORNHILL BRIGG MILL, THORNHILL BECK LANE,
BRIGHOUSE, WEST YORKSHIRE, HD6 4AH.

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

[Empty box for disclosure details]