



Trustees' Annual Report for the period

		Period start date			Period end date		
From	01	01	2022	To	31	12	2022

Section A Reference and administration details

Charity name

Other names charity is known by

Registered charity number (if any)

Charity's principal address

Milk Hall, Withens Lane,	
Barkisland	
Halifax	
Postcode	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	Secretary		Trustee committee/ charity members
3	Antonia East	Treasurer		Trustee committee/ charity members
4				
5				
6				
7				
8				

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)

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	
Trustee selection methods (eg. appointed by, elected by)	Appointed by the trustee team and elected by charity members

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.

All trustees and volunteers undergo induction and training as per our policy and procedure.

There are three trustees and two volunteers in 2022.

Sturge Weber UK has productive working relationships with the Sturge Weber Clinic at Great Ormond Street Hospital and with Dr Eriksson at UCLH.

The trustees conduct comprehensive risk assessments where needed.

Section C Objectives and activities

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

The Charity exists to promote the interests of people affected by Sturge Weber syndrome and to engage in any charitable activities which may assist their wellbeing and to protect and preserve the health of their families, friends and helpers, by providing information and support, promoting research into Sturge Weber syndrome and raising public and professional awareness of the syndrome.

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)

- Charitable purpose: to support the health and wellbeing of children/young people, adults, families and carers of people with Sturge Weber Syndrome through information, grants and signposting
- Provide a Family Weekend
- Support research

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.

We have a comprehensive list of statutory and non-statutory policies. Please see our website for statutory policies, other policies are available on request.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

The momentum of work by the Trustees carried forward into 2022. The audit of the Charity continues as does the review of our policies annually. The purpose of these are 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.

The first achievement of 2022 was to agree and launch the new logo. This resulted in the shop being restocked. The new shop was launched at the Family Weekend and the shop sales were £1990. Sales from the shop have increased during 2022. New stock is planned for 2023 so watch this space and visit www.sturgeweber.org.uk. The purchase of Square Reader allowed us to take card payments at the Family Weekend which meant the shop was available to all.

The beginning half of the year was taken up with organising the first Family Weekend that we have been able to hold since 2019 due to the Covid 19 restrictions. The Family Weekend was enjoyed by all that were able to attend. It took a more laid-back approach which was welcomed. 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, we were joined by MIND who gave a talk on mental health and Sarah Hodgkinson, Partner at Ramsden's solicitor who gave a talk on Wills, Probate and Trusts.

On Sunday we watched a presentation from Catherine Swales at Great Ormond Street Hospital on Sturge Weber Syndrome and were joined by Professor Simon Baron-Cohen via Zoom where he presented on Autism. Sunday afternoon was a whole family trip to Coombes Abbey Park, which was fantastic. Members who did not attend Coombes Abbey Park had the opportunity to use the hotel facilities and socialise.

The raffle was fantastic and ran over the course of Saturday and Sunday due to the generosity of members and supporters.

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 5th May to Monday 8th May 2023.

Fundraising in 2022 was increased which is incredible to see. Whilst payments out were increased because of the Family Weekend the receipts in the bank were £31,635 which after the payments out meant that the deficit to the Charity funds was only £6702. 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.

Active in April was again an enormous success and raised £4279. The community spirit this event brings is as important as the funds raised. It is the highlight of April for me to see our members and supporters' pictures shared of their miles and experiences raising money for our Charity.

Carolyn and I had the pleasure of joining the team at Great Ormond Street Hospital for an Away Day which was attended also by Antonia via Zoom. 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 Cuppa and Catch up for under 5s was started. During the day lots of discussions were had around transition and how they can support families in this process.

The Make a Difference Grant scheme continued in 2022. We were able to release 13 grants to members in 2022. 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. This is not limited to the items on the list, if there is something whether it be counselling for a parent, sibling or child/adult with Sturge Weber Syndrome or a piece of equipment every grant is discussed and considered according to the policy.

The AGM was arranged for July, but it had to be cancelled as a quorum was not achieved. The AGM will now be held at the Family Weekend in May. Members who are not in attendance can apply for a code to join via Zoom.

Two new features of 2022 have been the Cuppa and Catch Ups (for all and under 5s) and the Friends of Sturge Weber UK which have been set up.

The Cuppa and Catch Ups are an opportunity for us to catch up over Zoom and chat. They have been well received by members. The longest Cuppa and Catch Up was 3 hours and 40 minutes.

Many members helped at the Family Weekend in May and the idea of Friends of Sturge Weber UK was born. We already had 2 volunteers in Steve Waters, who runs the website and Nicola Colenso, who mentors me as Chair and delivers training and support for the Trustees. Three new volunteers have joined Friends of Sturge Weber UK, two of whom have Sturge Weber Syndrome. This is an exciting new venture for the Trustees and new volunteers are welcomed to join Friends of Sturge Weber UK.

The trustees elected to use a charity credit card to reduce administration and expense claims. The credit card will be used to make charity purchases, including items for successful grant applications. Using the card gives the charity legal protection on purchases and a clear audit trail.

Section D

Achievements and performance

Whilst fundraising and the shop are a good revenue source for the charity, we have during 2022 looked at external grant applications. We applied for a Pears Grant towards the Family Weekend. Despite being unsuccessful this time, we intend to apply for more external grant applications in 2023 with support from Nicola Colenso who has a wealth of knowledge on this.

Towards the end of 2022, we decided that the monthly updates would become bi-monthly updates. This allows me time during the two months to research useful information to share with members and whilst longer updates hopefully are well received by members.

The charity has moved forward considerably again in 2022 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 2023 is to work on member engagement and growing the Trustee team to strengthen the Charity.

Section E

Financial review

Brief statement of the charity's policy on reserves

The Charity aims to hold funds in reserve for the reasons detailed below.

Funding for other matters, e.g.:

- for projects suggested by Sturge Weber UK charity members,
- to aid research into Sturge Weber Syndrome,
- to raise awareness of SWS amongst professionals, families and the public,
- for people with SWS who are in need,
- ongoing support,
- one-off projects and support, will be covered by fundraising drives and grant applications.

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.

In 2022 we saw an increase in activity and engagement with the charity once the Covid-19 restrictions lifted. Sturge Weber UK continued to show a financially good position as of 31st December 2022, with the bank balance at £96,563.

Receipts in 2022 were £30,294 – 43% from campaigns and events, 23% from donations, 20% raised at the Family Weekend, 7% gift aid and 7% from the sale of shop items.

Payments from the account were £38,357 – 66% for the Family Weekend, 16% for projects, 10% for purchasing shop items and the remainder for operational costs.

Our largest expense and most valuable contribution to the charity's aims, is the Family Weekend. Due to popular request, we plan to hold the event annually.

The charity is run by volunteers, there are no paid staff. Travel and subsistence costs for trustee meetings are reimbursed. We have no investments.

Section F

Other optional information

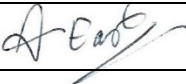
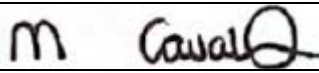
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Section G

Declaration

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

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Antonia East	MARIE CAVALIER
Position (eg Secretary, Chair, etc)	Treasurer	CHAIR
Date	07/09/2023	10/09/2023



Receipts and payments accounts

For the period from	Period start date 01-Jan-22	To	Period end date 31-Dec-22
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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	277	-	-	277	8
Gift Aid	2,049	-	-	2,049	1,355
Donations	7,011	-	-	7,011	6,066
Family Weekend	5,680	-	-	5,680	-
Fundraising	13,223	-	-	13,223	5,766
Shop	2,054	-	-	2,054	186
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	30,294	-	-	30,294	13,381
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	30,294	-	-	30,294	13,381
A3 Payments					
Accountancy Fees	696	-	-	696	696
Awareness	541	-	-	541	1,005
Communications	201	-	-	201	183
Equipment	179	-	-	179	-
Family Weekend	24,203	-	-	24,203	-
Fees	890	-	-	890	641
Gifts	38	-	-	38	-
Insurance	217	-	-	217	432
Memberships	85	-	-	85	173
Postage	539	-	-	539	993
Printing & Stationery	485	-	-	485	2,248
Projects	5,825	-	-	5,825	1,725
Purchases	3,924	-	-	3,924	-
Sundry	-	-	-	-	96
Telephone	-	-	-	-	66
Training	236	-	-	236	1,041
Trustee Meetings	298	-	-	298	1,362
	-	-	-	-	-
Sub total	38,357	-	-	38,357	10,658
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	38,357	-	-	38,357	10,658
Net of receipts/(payments)	- 8,063	-	-	- 8,063	2,723
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	89,626	15,000	-	104,626	-
Cash funds this year end	81,563	15,000	-	96,563	2,723

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Current Bank Account	29,723	-	-
	Deposit Bank Account	51,841	15,000	-
		-	-	-
	Total cash funds	81,563	15,000	-

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

OK

OK

OK


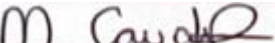
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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

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

	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
	Antonia East	07/05/2023
	MARIE CAVALIER	13/9/2023



Section A

Independent Examiner's Report

Report to the trustees

Charity Name

STURGE WEBER UK

**On accounts for the year
ended**

31 DECEMBER 2022

Charity no
(if any)

1016688

Set out on pages

3 - 10

(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 **31 / 12 / 2022**

**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:

15/09/2023

Name:

IFAT IQBAL JHUGROO

**Relevant professional
qualification(s) or body**

FCCA

(if any): SLEIGH & STORY LTD

Address: THORNHILL BRIGG MILL, THORNHILL BECK
LANE, BRIGGHOUSE, 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]