



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 6 April 2022 to 5 April 2023

Charity name: UK Infantile Spasms Trust

Charity registration number: 1172167

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The purpose of the charity is to provide a relief of the needs of those suffering from Infantile Spasms or West Syndrome, as well as promote awareness and support clinical research into infantile spasms.
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	As follows but not exclusively: a) The provision of information, advice and other assistance and support to children, parents, families and carers of those affected by Infantile Spasms b) The promotion of research into the causes and treatment of Infantile Spasms and the publication of useful results of this research c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	n/a

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	n/a
Policy on social investment including program related	Para 1.38	n/a

investment		
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>The charity provides support to around 1300 families with children affected by Infantile Spasms. This includes sharing information, education, support and grants.</p> <p>It also improves the awareness of the symptoms of Infantile Spasms across the general public as well as within medical professions.</p> <p>The charity also supports the advancement of clinical research into the condition to help children suffering now and in the future.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Achieving
Performance of fundraising activities against objectives set	Para 1.41	Achieving
Investment performance against objectives	Para 1.41	Profit is made annually therefore achieved
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	The charity was once again profit making, however donations received decreased due to less events and a general decline. The profit was £7,795 in 22/23
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	A significant percentage of the reserves currently held in the bank account have been ring-fenced for the imminent investment in a UKIST-owned primary healthcare education package which will roll out UK wide throughout 2024 and beyond (final payment expected to be made in Q4 2023).
Amount of reserves held	Para 1.22	£104,194
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	None

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	The charity's principal source of funds is from donations and fundraising events.
Investment policy and objectives including any social investment policy adopted	Para 1.46	None
A description of the principal risks facing the charity	Para 1.46	That not enough donations are made to keep the charity afloat. This doesn't seem to have been an issue in the accounting year and even through COVID previously.
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document	Para 1.25	Charitable Incorporated Organisation (CIO)
How is the charity constituted?	Para 1.25	Trust/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	Appointed by trustees normally at AGM

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	n/a
The charity's organisational structure and any wider network with which the charity works	Para 1.51	n/a
Relationship with any related parties	Para 1.51	n/a
Other		n/a

Reference and Administrative details

Charity name	UK Infantile Spasms Trust
Other name the charity uses	n/a
Registered charity number	1172167
Charity's principal address	28 Overnhill Road Downend Bristol BS16 5DN

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	Michelle Schofield			
2	Jenny Rawling			
3	Belen Robbins		Resigned 8 June 22	
4	Louisa Coyle			
5	Alice Goldhill			
6	Samia Sanders			
7	Amy Dowding			
8	Louise Derbyshire		Appointed 26 March 23	
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
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
Accountants	Norton Accountancy Ltd	7 Soundwell Road, Staple Hill, Bristol BS16 4QG

Name of chief executive or names of senior staff members (Optional information)

Not applicable

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Not applicable

Other optional information

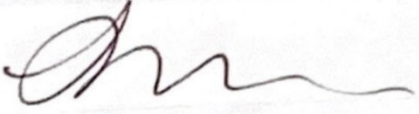
--

Declarations

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

Signed on behalf of the charity's trustees

Signature(s)

	
---	--

Full name(s)

Sarah Jenkins

Position (eg Secretary,
Chair, etc)

Advisor

Date

13 October 2023

Unaudited profit and loss report

for

UK Infantile Spasms Trust

Year ended 5 April 2023

Prepared: 7th June 2023
Finalised: 21st June 2023
By Norton Accountancy Ltd

ACCOUNTS FOR UKIST

FOR THE PERIOD ENDED 5 APRIL 2023

ACCOUNTANTS CERTIFICATE

We have prepared the attached accounts, without audit from the records and information supplied to us, and we confirm that they are in accordance therewith.

Jane Norton FMAAT
Norton Accountancy

Date

Licence no. 0521

CLIENT'S SIGNATURE

I have read the accounts prepared by Norton Accountancy and approve the figures

J Rawling

Signed

Date

M Scoffield

Signed

Date

UKIST**Profit & loss statement****Year ended 5 April 2023**

	<u>2023</u>		<u>2022</u>	
	<u>£</u>	<u>£</u>	<u>£</u>	<u>£</u>
<u>Income</u>				
Donations received		23,820		45,795
Grants				
		<u>23,820</u>		<u>45,795</u>
<u>Expenditure</u>				
Accountancy	300		300	
Grants	8,165		10,673	
Family support	1,213		2,217	
Insurance	439		439	
training and research	270		37	
Subs	216		90	
Promotional items	725		584	
Printing, postage & stationary	103		672	
Admin	2,827		939	
Sponsorship	1,597		762	
Sundry	269		24	
Social media & Website	<u>200</u>		<u>92</u>	
		16,025		16,830
Profit for the year		<u>7,795</u>		<u>28,965</u>