



**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From 6 April 2023 to 5 April 2024

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	<b>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.</b>
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	<b>As follows but not exclusively:</b> <b>a) The provision of information, advice and other assistance and support to children, parents, families and carers of those affected by Infantile Spasms</b> <b>b) The promotion of research into the causes and treatment of Infantile Spasms and the publication of useful results of this research</b> <b>c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives</b>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	<b>n/a</b>

### Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	Policy drafted / effective May 2024.
	Para 1.38	<b>n/a</b>

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

### Additional information (optional)

You may choose to include further statements where relevant about:

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

## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	<b>Financial position remains strong. Cash in bank allocated to future year budget, with sufficient funds to cover run costs.</b>
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	<b>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 for project is pending completion of work, expected H2 2024).</b>
Amount of reserves held	Para 1.22	<b>£ 104,494.00</b>
Reasons for holding zero reserves	Para 1.22	<b>n/a</b>
Details of fund materially in deficit	Para 1.24	<b>n/a</b>
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	<b>None</b>

### 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	<b>The charity's principal source of funds is from donations and fundraising events.</b>
Investment policy and objectives including any social investment policy adopted.	Para 1.46	<b>None</b>
A description of the principal risks facing the charity	Para 1.46	<b>Insufficient 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.</b>
Other		

## Structure, Governance and Management

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

### 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	<ul style="list-style-type: none"> <li>• <b>Charity Commission learning material (The essential trustee: what you need to know, what you need to do)</b></li> <li>• <b>DBS check</b></li> <li>• <b>NSPCC safeguarding course</b></li> <li>• <b>NVCO membership for ongoing Trustee support &amp; guidance</b></li> </ul>
The charity's organisational structure and any wider network with which the charity works	Para 1.51	<b>n/a</b>
Relationship with any related parties	Para 1.51	<b>n/a</b>
Other		<b>n/a</b>

## 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 Scoffield	Treasurer		
2	Jennifer Rawling	Chair		
3	Louisa Coyle			
4	Alice Goldhill			
5	Samia Sanders			
6	Amy Dowding			
7	Louise Derbyshire		Appointed 26 March 23	
8	Susan Blackburn		Appointed 24 February 24	UKIST AGM - Trustees
9	Kelly Skinner		Appointed 24 February 24	UKIST AGM - Trustees
10	Chloe Cox		Appointed 24 February 24	UKIST AGM - Trustees
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	None
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	None
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	None

### 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

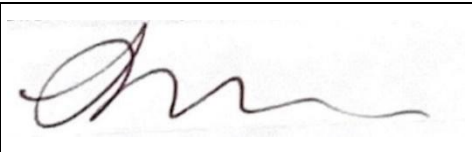
## Other optional information

Further information on 2023-2024 progress can be found here - [UKIST-update-2024.pdf \(ukinfantilepasmstrust.org\)](#)

## 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	16.1.25	



**Unaudited profit and loss report**

**for**

**UK Infantile Spasms Trust**

**Year ended 5 April 2024**

Prepared: 21st May 2024  
Finalised: 12th June 2024  
By Norton Accountancy Ltd

**ACCOUNTS FOR UKIST**

**FOR THE PERIOD ENDED 5 APRIL 2024**

**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

S Blackburn

\_\_\_\_\_  
Signed

\_\_\_\_\_  
Date

M Scoffield

\_\_\_\_\_  
Signed

\_\_\_\_\_  
Date

**UKIST****Profit & loss statement****Year ended 5 April 2024**

	<b><u>2024</u></b>		<b><u>2023</u></b>	
	<b><u>£</u></b>	<b><u>£</u></b>	<b><u>£</u></b>	<b><u>£</u></b>
<i><u>Income</u></i>				
Donations received		44,248		23,820
Grants		-		-
		<u>44,248</u>		<u>23,820</u>
<i><u>Expenditure</u></i>				
Accountancy	600		-	
Bank charges	40		-	
Grants	11,583		8,165	
Family support	1,784		1,213	
Insurance	441		439	
Training and research	793		270	
Subs	446		216	
Promotional items	1,585		725	
Printing, postage & stationary	293		103	
Admin	1,889		2,827	
Sponsorship	4,152		1,597	
Sundry	136		269	
Social media & website	92		200	
		<u>23,833</u>		<u>16,024</u>
<b>Profit for the year</b>		<b><u>20,415</u></b>		<b><u>7,796</u></b>



Section A

Independent Examiner's Report

Report to the trustees/  
members of

Charity Name  
UK Infantile Spasms Trust

On accounts for the year  
ended

5<sup>th</sup> April 2024

Charity no  
(if any)

1172167

Set out on pages

1+2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 05/04/2020.

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: 16.1.25

Name: SARAH JENKINS

Relevant professional  
qualification(s) or body

FMAAT

Address:

Norton Accountancy Ltd  
7 Soundwell Road  
Bristol BS16 4QG

**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.**

None – the charity appears to be well run with no concerns.