



**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From 6 April 2021 to 5 April 2022

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</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	<b>n/a</b>
Policy on social investment including program related investment	Para 1.38	<b>n/a</b>

Other		
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## 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>The charity has performed well since COVID and donations received increased leaving a profit of £28965 in 21/22</b>
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	<b>The reserves are held in the charity to cover future costs should there be a period where donations and fundraising efforts do not cover this. Talks are to take place about distributing this to protect the funds and using some of the money to build some UKIST own education materials</b>
Amount of reserves held	Para 1.22	<b>£95,473</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>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</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	<b>n/a</b>
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 Schofield			
2	Jenny Rawling			
3	Belen Robbins			
4	Louisa Coyle			
5	Alice Goldhill			
6	Samia Sanders			
7	Amy Dowding		26 March 2022	Appointed at AGM
8				
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
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## Exemptions from disclosure

Reason for non-disclosure of key personnel details

**Not applicable**

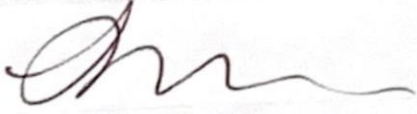
## Other optional information

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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)		
Full name(s)	Sarah Jenkins	
Position (eg Secretary, Chair, etc)	Advisor	
Date	2 November 2022	

**Unaudited profit and loss report**

**for**

**UK Infantile Spasms Trust**

**Year ended 5 April 2022**

Prepared: 31st May 2022  
Finalised: 8th June 2022  
By Norton Accountancy Ltd



**ACCOUNTS FOR UKIST**

**FOR THE PERIOD ENDED 5 APRIL 2022**

**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 Rawlings

\_\_\_\_\_  
Signed

\_\_\_\_\_  
Date

M Scoffield

\_\_\_\_\_  
Signed

\_\_\_\_\_  
Date

**UKIST**  
**Profit & loss statement**  
**Year ended 5 April 2022**

	<b><u>2022</u></b>		<b><u>2021</u></b>	
	<b><u>£</u></b>	<b><u>£</u></b>	<b><u>£</u></b>	<b><u>£</u></b>
<b><u>Income</u></b>				
Donations received		45,795		32,998
Grants		-		7,083
		<u>45,795</u>		<u>40,081</u>
<b><u>Expenditure</u></b>				
Accountancy	300		300	
Grants	10,673		2,816	
Family support	2,217		5,121	
Insurance	439		431	
training and research	37		6,349	
Subs	90		150	
Promotional items	584		361	
Printing, postage & stationary	672		237	
Admin	939		-	
Sponsorship	762		-	
Sundry	24		-	
Social media & Website	<u>92</u>		<u>176</u>	
		16,830		15,949
<b>Profit for the year</b>		<b><u>28,965</u></b>		<b><u>17,049</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 2022

**Charity  
no (if  
any)**

1172167

**Set out on pages**

1+2

**Responsibilities and  
basis of report**

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

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:**

24/10/2022

**Name:**

SARAH JENKINS

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

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.

