

Trustees' Annual Report for the period						
		Period start date			Period end date	
From	01	04	2024	To	31	03 2025

Section A Reference and administration details

Charity name

UK Infantile Spasms Trust

Other names charity is known by

UKIST

Registered charity number (if any)

1172167

Charity's principal address

28 Overnhill Road

Bristol

Postcode

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	Jenny Rawling	Chair		
2	Susan Blackburn	Treasurer		
3	Michelle Scoffield			
4	Louisa Coyle			
5	Alice Goldhill			
6	Samia Sanders			
7	Amy Dowding			
8	Louise Derbyshire			
9	Kelly Skinner			
10	Chloe Cox			
11				
12				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	
N/A	

Names and addresses of advisers (optional information)

Type of Adviser	Name	Address

Name of Chief Executive or names of Senior staff members (optional information)

Name	Dates acted if not for whole year
N/A	

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Charitable Incorporated Organisation (CIO)
How the charity is constituted (eg. trust, association, company)	Trust / CIO
Trustee selection methods (eg. appointed by, elected by)	Appointed by Trustees at the Annual General Meeting (AGM)

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.

<p>Charity Commission learning material (The essential trustee: what you need to know, what you need to do)</p> <p>DBS check</p> <p>NSPCC safeguarding course</p> <p>NCVO membership for ongoing Trustee support & guidance</p> <p>A new Trustee induction process is underway</p> <p>The charity is strengthening the wider networks by attending national medical conferences with plans to attend the Infantile Spasms Action Network (ISAN) conference in Washington, USA.</p> <p>Membership of UK RET, CREA and ISAN</p> <p>Trustees are reimbursed for travel expenses for attending charity events and the AGM. The expense policy is derived from the Charity Commission guidance.</p> <p>A conflict-of-interest policy is in place; a conflict register is in place and conflict of interest is an agenda point at the monthly Board meetings</p> <p>A risk policy is in place; the risk register is updated as required by the Chair and Treasurer with a full annual review by the Board</p>

Section C Objectives and activities

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

The purpose of the charity is to provide 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 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)

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. Granting £10,000 funding to the BEE Project at Kings College hospital with further commitment to supporting infantile Spasms projects in 2025.
- c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives. The medical education training course is in the final stages of completion and will be launched in 2025-26.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

UKIST has a documented grant award policy which is reviewed annually. The grant criteria and application form are on the website and are reviewed annually alongside the policy.

UKIST has a system for managing processes and policies and this is reviewed annually by the Board

Trustees and the Facebook admin team are volunteers. Their contribution, knowledge and skills ensure that the charity is managed effectively, and that it is sustainable.

Over the next 12 months UKIST will be working with The Cranfield Trust to develop their strategy and business plan, which will lead to charity growth and long-term plans to appoint staff.

Summary of the main achievements of the charity during the year

Review UKIST's annual newsletter, follow the link below

[newsletter_2025.pdf](#)

Section E

Financial review

Brief statement of the charity's policy on reserves

The charity has a reserves policy and has made great strides in actioning the necessary steps to ensure reserves are managed well, not only in terms of including 3 months operational costs but it also has designated funds for future expenditure commitments.

Details of any funds materially in deficit

Not applicable

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.

The charity's principal source of funding is by families affected by infantile spasms (IS), family friends and charity Trustees. £20,000 was generously donated by The Phillips 2012 Charitable Trust. In April 2025 UKIST will participate in the London Landmark Half Marathon (LLHM) and will be looking to expand on including participatory events in future.

A new fundraising initiative is in progress, UKIST has applied to The Spectris Foundation for a £5,000 grant to deliver a health and wellbeing project for parents of IS babies/children. A Spectris employee, also a member of the UKIST Facebook group, nominated UKIST for the grant award.

Expenditure is managed via a budget to ensure that costs are controlled, and it is a point on the monthly Board meetings agenda. The annual budget is set at the Annual General Meeting (AGM) and budget variations are reviewed regularly to ensure funding is available to achieve the charity's key objectives.

The Xero finance system has recently been introduced to provide accounting management and relevant income and expenditure reporting. This affords all Trustees full oversight as well as providing read-only access to the current bank account transactions.

A high interest, 60-day term new account will protect funds above £85,000, as per FSCS guidance. The bank of choice reinvests all its profits into the charity sector. Drafting an investment policy is in future plans.

Section F

Other optional information

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		
Position (e.g. Secretary, Chair etc)		
Date		

Unaudited accounts

UK Infantile Spasms Trust

Year ended 31 March 2025

Prepared: 20th May 2025
Finalised: 15th July 2025
By Norton Accountancy Ltd

ACCOUNTS FOR UKIST
FOR THE PERIOD ENDED 31 MARCH 2025
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

31 / 07 / 2025

Date

Licence no. 0521

CLIENT'S SIGNATURE

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

S Blackburn



Signed

03 / 08 / 2025

Date

J Rawling



Signed

07 / 08 / 2025

Date

UKIST**Profit & loss statement****Year ended 31 March 2025**

	<u>2025</u>		<u>2024</u>	
	<u>£</u>	<u>£</u>	<u>£</u>	<u>£</u>
<u>Income</u>				
Donations received		67,099		44,248
Grants		<u>20,000</u>		<u>-</u>
		87,099		44,248
<u>Expenditure</u>				
Accountancy	522		600	
Bank charges	202		40	
Computer	4		-	
Grants	11,365		11,583	
One-off research donation	10,000		-	
Medical platform	9,492		-	
Family support	299		1,784	
Insurance	365		441	
Training and research	307		793	
Subs	562		446	
Promotional items	713		1,585	
Printing, postage & stationary	281		293	
Admin	2,846		1,889	
Sponsorship	2,952		4,152	
Sundry	353		136	
Social media & website	<u>92</u>		<u>92</u>	
		40,354		23,833
Profit for the year		<u>46,744</u>		<u>20,415</u>

UKIST
Balance sheet
Year ended 31 March 2025

	<u>2025</u>		<u>2024</u>
<u>Current assets</u>			
Bank balance	152,823		124,909
Accrued income	20,192		-
Prepayments	<u>3,072</u>		<u>-</u>
	176,087		124,909
<u>Current liabilities</u>			
Accruals	-4,734		-300
Total assets less liabilities	<u>171,353</u>		<u>124,609</u>
Retained profits b/fwd	124,609		104,194
Profit in year	46,744		20,415
Retained profits c/fwd	<u>171,353</u>		<u>124,609</u>

Notes to the accounts

1 - Restricted reserves

Going forward the trustees will be recognising restricted reserves to cover certain projects or investments. As at 31.3.2025, these were identified as totalling £62,343 for the investments in a medical education platform, on-going research costs and grants to families.

In addition, overheads for the next 12 months have also been restricted from spending so there is a contingency buffer in place to cover any drop in income. This totalled £9,541 and covers items such as AGM costs, conference costs, software, admin and various other smaller annual costs.

On that basis, the total restricted reserves at 31.3.2025 were £71,884. Going forward, the following note will be included:

	<u>Restricted</u> <u>for research</u> <u>& projects</u>	<u>Restricted</u> <u>overhead</u> <u>fund</u>	<u>Unrestricted</u> <u>Income</u> <u>Funds</u>	<u>£</u>
At 01.04.2024	-	-	124,609	124,609
Net incoming resources	-	-	46,744	46,744
Reallocation of reserves per note	62,343	9,541	- 71,884	-
At 31.03.2025	<u>62,343</u>	<u>9,541</u>	<u>99,469</u>	<u>171,353</u>



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
UK Infantile Spasms Trust

On accounts for the year
ended

5th April 2025

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:

3.7.25

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.