CHARITY COMMISSION FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From **01/01/2025** **To** **31/12/2025**

Charity name:
A Rare Cause
Charity registration number:
1198461

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The advancement of health or the saving of lives in relation to the global rare disease community, in particular by providing information and resources to raise knowledge and increase awareness (as set out in the charity's governing document).
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	During the period the charity supported diagnostic and clinical service delivery for rare disease patients in South Africa under a service level agreement with Rare Diseases South Africa; received and began administering a major grant from Direct Relief for the LSD-Impact programme; and undertook advocacy, education and awareness-raising activity, including participation in international rare disease conferences and working groups and patient storytelling content.
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees confirm that they have had regard to the Charity Commission's general guidance on public benefit in exercising their powers and duties, and are satisfied that the charity's aims and activities deliver public benefit consistent with its objects.

Additional information (optional)
You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	Grants and programme funding are made to partner organisations delivering rare disease diagnostic and support services overseas, under written service level agreements, with outcomes reported back to the trustees.
Policy on social investment including program related investment	Para 1.38	Not applicable – the charity does not hold funds for social investment.

Contribution made by volunteers	Para 1.38	Two volunteers supported the charity's activities during the period, in addition to the trustees.
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	The charity secured and began administering a significant grant from Direct Relief in support of its Lysosomal Storage Disease (LSD)-Impact rare disease programme, and continued to fund diagnostic support delivered in South Africa through its partner, Rare Diseases South Africa. Trustees and representatives strengthened ARC's international standing through participation in the International Rare Diseases Consortium Assembly (IRDiRC), the International Working Group on Gaucher Disease and the International MPS Society meeting, and through webinars with Rare Disease International, the African Society for Laboratory Medicine and other partners. Work also began on a flagship African-focused Gaucher disease/iPSC research initiative, and the charity's public advocacy and patient-storytelling activity (including a documentary on MPS I) extended its reach as a credible voice on rare disease and global health equity.

Additional information (optional)
You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Diagnostic support in South Africa continued under the service level agreement with Rare Diseases South Africa, and the charity began work on developing the first African-derived iPSC models for Gaucher disease research, in collaboration with academic partners in the USA.
Performance of fundraising activities against objectives set	Para 1.41	The charity received a major grant from Direct Relief for the LSD-Impact programme and initiated a grant application to the Michael J. Fox Foundation to fund a two-year postdoctoral research role supporting the Gaucher/iPSC initiative.
Investment performance against objectives	Para 1.41	Not applicable – the charity does not hold an investment portfolio; funds are held as cash.

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Total income for the period was £25,372 (2024: £120), principally a grant of £25,342 from Direct Relief together with £30 of donations. Total spending was £2,007, including £552 spent on the charity's programme in South Africa (of which £502 was paid as a grant to Rare Diseases South Africa) and the balance on administration, travel and banking costs. The charity held cash funds of £23,485.49 at 31 December 2025 (2024: £120), all as unrestricted funds.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The trustees aim to hold reserves sufficient to cover the charity's core running costs and committed programme spend, noting that the majority of funds held at the year end are earmarked for the LSD-Impact programme.
Amount of reserves held	Para 1.22	Total cash held was £23,485.49 at the year end, the majority of which is committed to the LSD-Impact programme.
Reasons for holding zero reserves	Para 1.22	Not applicable – the charity held cash reserves at the year end.
Details of fund materially in deficit	Para 1.24	None.
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	The trustees have no material uncertainties about the charity's ability to continue as a going concern.

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 funds are principally derived from grants from international foundations and NGOs (including Direct Relief) and from individual donations.
Investment policy and objectives including any social investment policy adopted	Para 1.46	The charity does not hold an investment portfolio. Funds not immediately required are held as cash with Wise Payments Ltd and, from 2026, CAF Bank.
A description of the principal risks facing the charity	Para 1.46	The principal risks identified by the trustees are: reliance on a small number of grant funders and the risk of funding not being renewed; foreign exchange and payment-transfer risk on funds sent to support overseas programmes; and the capacity of a small, wholly volunteer trustee board to manage growth in the charity's activities.

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	Constitution (Charitable Incorporated Organisation – Foundation model), registered with the Charity Commission on 31 March 2022.
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	A Rare Cause is constituted as a Charitable Incorporated Organisation (CIO) – Foundation model.
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	Trustees are appointed by the existing trustees in accordance with the charity's constitution.

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	During the year, the trustees developed, reviewed and formally adopted policies covering bullying and harassment, international financial controls, risk management, and safeguarding. These policies are intended to support appropriate governance, oversight, and protection of the charity, its beneficiaries, volunteers, and other stakeholders.
The charity's organisational structure and any wider network with which the charity works	Para 1.51	The charity is governed by a board of trustees (four trustees during the period) and has no employees; day-to-day activity is carried out by trustees and volunteers.
Relationship with any related parties	Para 1.51	No related party transactions were identified during the period; grant recipients were not related parties to the charity.

Reference and Administrative details

Charity name	A Rare Cause
Other name the charity uses	ARC
Registered charity number	1198461
Charity's principal address	6 The Green, Ilkley, LS29 7FF

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	Prof Amaka Offiah		Whole year	
	2	Dr Dumebi Oderinde		Whole year	
	3	Tiffany Wong		Whole year	
	4	Linda Ebosie		From 18 June 2025	
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	20				

Corporate trustees – names of the directors at the date the report was approved

Director name		
Not applicable – A Rare Cause is a Charitable Incorporated Organisation and does not have corporate trustees.		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	
Not applicable – no assets are held in the names of individual trustees.		

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	Not applicable – the charity does not act as custodian trustee for other charities.
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
	Bankers	Wise Payments Ltd	1st Floor, Worship Square, 65 Clifton Street, London EC2A 4JE
	Bankers	CAF Bank Ltd	(account opened 2026, after this reporting period)
	Name of chief executive or names of senior staff members (Optional information)		
	None – the charity has no employees; activities are undertaken by trustees and volunteers.		

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Not applicable – no exemption from disclosure has been applied.

Other optional information

Further detail on the charity's activities and strategic priorities during the period is set out in the Trustees' Update Report (June 2026), available separately.

Declarations

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

Signed on behalf of the charity's trustees

Signature(s)	Tiffany Wong
Full name(s)	Tiffany Wong
Position (eg Secretary, Chair, etc)	Secretary
Date	October 25 2026

A RARE CAUSE

Financial Statements
For the year ended 31 December 2025

Registered number: 1198461

CONTENTS

Legal and administrative information	Page 1
Statement of financial activities	Page 2
Balance sheet	Page 3

Trustees

L. Ebosie
A. Offiah
D. Oderinde
T. Wong

Charity Registered Number - 1198461

Registered Office

6 The Green
Burley In Wharfedale
Ilkley
West Yorkshire
LS29 7FF

Accountants

Bloomfield's
Bloomfield Court
76 Factory Street West
Atherton, Manchester
M46 0EF

A RARE CAUSE
STATEMENT OF FINANCIAL ACTIVITIES AND BALANCE SHEET
FOR THE YEAR ENDED 31 DECEMBER 2025

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total funds 2025 £	*Total funds 2024 £*
INCOMING RESOURCES				
Grants received	**25,342**	**-**	**25,342**	**-**
Transfers from/to Deferred Income	**(22,965)**	**-**	**(22,965)**	**-**
	2,377	**-**	**2,377**	**-**
Fundraising	**-**	**-**	**-**	**-**
Donations	**30**	**-**	**30**	**120**
TOTAL INCOMING RESOURCES	**2,407**	**-**	**2,407**	**120**
RESOURCES EXPENDED				
Direct Charitable Expenditure				
Travel	**1,499**	**-**	**1,499**	**-**
Bank Charges	**6**	**-**	**6**	**-**
Grants Made	**502**	**-**	**502**	**-**
Accountancy & Secretarial	**400**	**-**	**400**	**-**
TOTAL RESOURCES EXPENDED	**2,407**	**-**	**2,407**	**-**
NET INCOMING / (OUTGOING) RESOURCES BEFORE TAXATION	**-**	**-**	**-**	**120**
Taxation	**-**	**-**	**-**	**-**
NET MOVEMENT IN FUNDS	**-**	**-**	**-**	**120**
Fund balances at 1 April 2024	**120**	**-**	**120**	**-**
FUND BALANCES AT 31 March 2025	**120**	**-**	**120**	**120**

A RARE CAUSE
STATEMENT OF FINANCIAL ACTIVITIES AND BALANCE SHEET
FOR THE YEAR ENDED 31 DECEMBER 2025

	2025		2024	
	£	£	£	£
CURRENT ASSETS				
Cash and bank in hand	**23,485**		120	
	23,485		120	
CREDITORS: Amounts falling due within one year	**(23,365)**		-	
Net current assets		**120**		120
TOTAL ASSETS LESS CURRENT LIABILITIES	**120**		120	
NET ASSETS	**120**		120	
CHARITY FUNDS				
Restricted funds		**120**		120
Unrestricted funds		**-**		-
		120		120

The directors and trustees consider that the company is entitled to exemption from the requirement to have an audit under the provisions of S.480 of the Companies Act 2006.

No notice from the members under S.476 of the Companies Act 2006 requiring the company to have an audit has been deposited with the company.

The directors and trustees acknowledge their responsibility for ensuring that the company keeps accounting records which comply with S.386 of the Companies Act 2006, and for preparing accounts, which give a true and fair view of the state of the affairs of the company at 31st December 2025 and of its net expenditure for the year then ended in accordance with the requirements of S.396, but which otherwise comply with the requirements of the Act relating to the accounts so far as applicable to the company.

The financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

These financial statements were approved by the Trustees on October 25, 2026 and signed on their behalf, by:

Tiffany Wong

Director

Date October 25, 2026

6 The Green
Ilkley LS29 7FF
United Kingdom
Registered charity in England & Wales
Registration: 1198461

Charity commission

We believe independent auditors report is not required due to income level but audited accounts are attached and signed by trustee representative.

KR

Christian Hendriksz (Prof)
Chief Community Impact Officer

