



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

Period start date: 01 January 2024 **Period end date:** 31 December 2024

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 Objects of the CIO are the advancement of health and 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.
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	ARC was only able to establish a currency account because we could not find a UK bank willing to allow us to open an account with them.
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 they have had regard to the guidance issued by the Charity Commission.

Additional information

	SORP reference	
Policy on grant making	Para 1.38	Not applicable
Policy on social investment including program related investment - Para 1.38		
Contribution made by volunteers	Para 1.38	The CIO currently has two volunteers: one serving as the Chief Community Impact Officer (CCIO) and another as the Operational Lead, although the latter position has been inactive due to a lack of funding. These roles are dedicated to advancing the ARC's strategy, formulating and upholding policies, and engaging with potential donors now that a bank account has been established. The CCIO remains

		committed to working pro bono in the absence of financial support.
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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	Despite lacking funding, the charity remains committed to supporting various projects in Low- and Middle-Income Countries (LMIC), particularly in Sub-Saharan Africa. During the reporting year, the Africa Roadmap project continued to gain traction, aiding families impacted by rare diseases in the target nations. The Chief Charity Impact Officer (CCIO) successfully presented at several international meetings to enhance the charity's visibility. Additionally, this project showcased a poster at an international conference, and a publication is currently in the works.

Additional information

Achievements against objectives set	Para 1.41	N/A
Performance of fundraising activities against objectives set	Para 1.41	N/A
Investment performance against objectives	Para 1.41	N/A
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	£120
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	None
Amount of reserves held	Para 1.22	None
Reasons for holding zero reserves	Para 1.22	No activity or employees
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	N/A

Additional information

The charity's principal sources of funds (including any fundraising)	Para 1.47	None
Investment policy and objectives including any social investment policy adopted	Para 1.46	
A description of the principal risks facing the charity	Para 1.46	
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document	Para 1.25	Foundation CIO Constitution
How is the charity constituted?	Para 1.25	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	<p>Appointment of charity trustees</p> <ol style="list-style-type: none"> 1. Apart from the first charity trustees, every trustee must be appointed for a term of three years by a resolution passed at a properly convened meeting of the charity trustees. 2. In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Additional information

Policies and procedures adopted for the induction and training of trustees	Para 1.51	
The charity's organisational structure and any wider network with which the charity works	Para 1.51	The Board of Trustees ensures effective governance while the Chief Clinical Information Officer (CCIO) actively promotes the charity and undertakes necessary tasks. The charity collaborates with various patient organisations, academic institutions, and healthcare professionals throughout Sub-Saharan Africa.
Relationship with any related parties	Para 1.51	FYMCA Medical Ltd, the parent company, continues to provide support to the charitable arm through network development and specialised expertise.

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, Burley in Wharfedale, Ilkley, LS29 7FF

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Dumebi Oderinde	Chair		
2	Tiffany Wong	Secretary		
3	Amaka Offiah			
4	Linda Ebosie		Starting from 9/29/2025	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	N/A
Name and objects of the charity on whose behalf the assets are held and how this fall within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

Declaration

Full name	Dumebi Oderinde
Position	Chair
Signature	
Date	23/10/2025