Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day	Month	Year		Day	Month	Year
	01	JAN	2025		31	DEC	2025

Section A Reference and administration details

Charity name	ACTION FCS
Other names charity is known by	
Registered charity number (if any)	**1165873**
Charity's principal address	36 Gaskell St, London
Postcode	**SW4 6NS**

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	Jill Prawer	Chair		
2	Helen Aderin			
3	Pat Wade	Treasurer		
4	Finian Nicholas Patrick Day-Lewis			
5	Helga Davidson		Appointed 18/April 2025	Board of Trustees
6	Catherine Rachel Wynne Brun		Appointed 16 July 2026	Board of Trustees

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution

How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation
Trustee selection methods (eg. appointed by, elected by)	Appointed by Board of Trustees

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.

Trustees are selected having regard to the skills and experience needed to run a small organisation, along with having an understanding and/or experience of FCS or similar conditions.

All new Trustees are provided with a copy of the constitution and past packs of Board papers, which include policies and procedures approved by the Board.

The charity is run by a volunteer board of trustees, the chair of which (and founder) is the main operational executive.

The Charity works with related networks: Heart UK, Diabetics UK, Genetic Alliance, Rare Disease UK, RareConnect.

Section C Objectives and activities

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

The objects of the CIO are to relieve sickness and preserve and protect good health of persons suffering from Familial Chylomicronaemia Syndrome (FCS) and related conditions by:

1. raising awareness of FCS and related conditions;
2. educating patients, medical personnel and the public in general about FCS;
3. supporting people with FCS and those affected by it to live a full, healthy and integrated life;

advocating for access to excellent care and new medicines for all patients with FCS

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)

The charity endeavours to promote learning and provide information on the condition of FCS on its website and social media platforms for patients, their families and medical professionals.

Workshops and presentations to talk about FCS are attended and delivered to promote awareness of the condition.

During the year, the Charity worked closely with pharmaceutical organisations looking to develop new drugs for the condition of FSC.

In the period to 31 December 2025, the trustees have had regard to the guidance issued by the Charity Commission at all times.

Additional details of objectives and activities (Optional information)

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

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

Section D Achievements and performance

Summary of the main achievements of the charity during the year

During the year we continued to support and network with organisations with interest in FCS and associated conditions.

Workshops and conferences were attended for information sharing and advocacy work.

We continued to manage the website for the Charity and a Whatsapp group for the international FCS community. In addition, the Charity supported FCS Awareness Day.

Section E Financial review

Brief statement of the charity's policy on reserves	Currently, the Charity does not have any of its unrestricted funds in the Bank set aside as a reserve and no policy exists. All cash funds are unrestricted and sufficient to cover operations and associated risks for more than one year.
Details of any funds materially in deficit	None

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 received two grants during the year the purpose of which was to fund an informative conference for patients and their carers. The conference was held in February 2026.

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)	Patricia Wade	
Position (eg Secretary, Chair, etc)	Treasurer	
Date	30 October 2026	

CHARITY COMMISSION FOR ENGLAND AND WALES

ACTIONFCS	1165873

Receipts and payments accounts

CC16a

For the period from	1012025	To	31122025

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Grant Arrowhead	18,800		-	18,800	-
Grant Sobi	18,800		-	18,800	-
Genetic Alliance Conference	125		-	125	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
***Sub total** (Gross income for AR)*	37,725	-	-	37,725	200
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	37,725	-	-	37,725	200
A3 Payments					
Membership subscriptions and Regulation	98	-	-	98	-
Conferences, Meetings, Consultancy	6,953	-	-	6,953	-
Mobile	96	-	-	96	-
IT	446	-	-	446	-
Insurance	165	-	-	165	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	7,758	-	-	7,758	415
A4 Asset and investment purchases, (see table)					
PC	649	-	-	649	
	-	-	-	-	
Sub total	649	-	-	649	-
Total payments	8,407	-	-	8,407	415
Net of receipts/(payments)	29,318	-	-	29,318	215
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	29,309	-	-	29,309	-
Cash funds this year end	58,627	-	-	58,627	215

Section B Statement of assets and liabilities at the end of the period

B1 Cash funds

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Lloyds Bank current business account	58,627	-	-
		-	-	-
		-	-	-
	Total cash funds	58,627	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

B2 Other monetary assets

Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

B3 Investment assets

Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
		-	-
		-	-
		-	-
		-	-
		-	-

B4 Assets retained for the charity's own use

Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
PC	Unrestricted	649	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-

B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)	When due (optional)
		-	
		-	
		-	
		-	
		-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Patricia Wade	30-Oct-26

CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of	Charity Name ACTION FCS		
On accounts for the year ended	31 December 2025	**Charity no (if any)**	**1165873**
Set out on pages	1 - 2 (remember to include the page numbers of additional sheets)		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 /12 / 2025.

Responsibilities and basis of report

As the charity trustees of the Trust, 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 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 (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

* *Please delete the words in the brackets if they do not apply.*

Signed:	Nnamdi Obiosa	**Date:**	21/10/2026
Name:	Dr Nnamdi Obiosa		
Relevant professional qualification(s) or body (if any):	B.Sc., MBA, Ph.D., MIC, FCMI, ACMA, CGMA, MiP, FAIA (Acad). Regulated by Chartered Institute of Management Accountants.		
Address:	C & N Consults Ltd 207 Streatham High Road London SW16 6EG		

Section B	Disclosure
	Only complete if the examiner needs to highlight 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