



CHARITY COMMISSION  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From **1 January 2023** Period start date To **31 December 2023** Period end date

Charity name: **Action FCS**

Charity registration number: **1165873**

## Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	<p>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:</p> <ol style="list-style-type: none"><li>1. raising awareness of FCS and related conditions;</li><li>2. educating patients, medical personnel and the public in general about FCS;</li><li>3. supporting people with FCS and those affected by it to live a full, healthy and integrated life;</li></ol> <p>advocating for access to excellent care and new medicines for all patients with FCS</p>
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	<p>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.</p> <p>Workshops and presentations to talk about FCS are attended and delivered to promote awareness of the condition.</p>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	<p>In the period to 31 December 2024, the trustees have had regard to the guidance issued by the Charity Commission at all times.</p>

**Additional information (optional)**

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	
Policy on social investment including program related investment	Para 1.38	
Contribution made by volunteers	Para 1.38	
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	<p>During the year we continued to support and network with organisations with interest in FCS and associated conditions.</p> <p>Workshops and conferences were attended for information sharing and advocacy work.</p> <p>We continued to manage the facebook group FCS Community, and ran the annual FCS Awareness Day,</p>

**Additional information (optional)**

You may choose to include further statements where relevant about:

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



## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	At the end of the period, cash funds in the Bank amounted to £29, 309. Receipts during the year totalled £200, whilst payments amounted to £415, showing a small net deficit for 2024 of £215.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	Currently, the Charity does not have any of its unrestricted funds in the Bank set aside as a reserve and no policy exists.
Amount of reserves held	Para 1.22	None
Reasons for holding zero reserves	Para 1.22	All cash funds are unrestricted and sufficient to cover operations and associated risks for more than one year.
Details of fund materially in deficit	Para 1.24	
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	

### 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 main sources of income are through other organisations and groups seeking knowledge and advice on Familial Chylomicroneamia Syndrome. The Charity also receives a small number of donations.
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	<p>- No significant funding or regular income for the Charity.</p> <p>-In the long term, the Charity is very dependent on grant funding from Pharmaceutical organisations with vested interests in bringing potential new drugs to the market for the treatment of FCS and associated conditions. No grant funding of this nature is currently being received.</p> <p>- Challenges for Trustee recruitment and retention</p>
Other		

## Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	Constitution
How is the charity constituted? (e.g. unincorporated association, CIO)	Para 1.25	Charitable Incorporated Organisation
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	Appointed by the Trustee Board

### 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	<p>Trustees are selected having regard to the skills and experience needed to run a small organisation, along with having understanding and/or experience of FCS or similar conditions.</p> <p>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.</p>
The charity's organisational structure and any wider network with which the charity works	Para 1.51	<p>The charity is run by a volunteer board of trustees, the chair of which (and founder) is the main operational executive. The Treasurer is a qualified Chartered Company Secretary.</p> <p>The Charity works with related networks: Heart UK, Diabetics UK, Genetic Alliance, Rare Disease UK, RareConnect.</p>
Relationship with any related parties	Para 1.51	
Other		



## Reference and Administrative details

Charity name	Action FCS
Other name the charity uses	
Registered charity number	1165873
Charity's principal address	36 Gaskell St, London 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			
4	Pat Wade	Treasurer		
5	Finian Nicholas Patrick Day-Lewis			

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

[illegible]

Name of trustees holding title to property belonging to the charity

[illegible]

## 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

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

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## Exemptions from disclosure

Reason for non-disclosure of key personnel details

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## 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)	PATRICIA WADE	
Position (eg Secretary, Chair, etc)	TREASURER	
Date	17/9/25	





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Action FCS

1165873

## Receipts and payments accounts

CC16a

For the period  
from

10/12/24

To

31/12/24

### 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 £
<b>A1 Receipts</b>					
Conference meetings	200	-	-	200	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	200	-	-	200	338
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-
<b>Total receipts</b>	200	-	-	200	338
<b>A3 Payments</b>					
Membership subscriptions	38	-	-	38	-
Regulatory fees	60	-	-	60	-
Insurance	165	-	-	165	-
Mobile phone operation	8	-	-	8	-
IT	144	-	-	144	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	415	-	-	415	787
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-
<b>Total payments</b>	415	-	-	415	787
<b>Net of receipts/(payments)</b>	215	-	-	215	449
<b>A5 Transfers between funds</b>	-	-	-	-	-
<b>A6 Cash funds last year end</b>	29,524	-	-	29,524	29,973
<b>Cash funds this year end</b>	29,309	-	-	29,309	29,524

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		-	-	-
		-	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>29,309</b>	-	-
(agree balances with receipts and payments account(s))				

[illegible]

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B3 Investment assets</b>			-	-
			-	-
			-	-
			-	-
			-	-

[illegible]

35 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

Purple

PATRICIA VANDER

approval
17/9/25