



Trustees' Annual Report for the period

Period start date
From Day 01 Month 01 Year 2022 To Day 31 Month 12 Year 2022

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	Catherine Brun		Resigned 15 December 2022	
4	Pat Wade	Treasurer		
5	Finian Nicholas Patrick Day-Lewis			
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

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

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Lloyds Bank	Victoria Branch, PO Box 1000, BX1 1LT	

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

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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document	Constitution
How the charity is constituted	Charitable Incorporated Organisation
Trustee selection methods	Appointed by the Trustee Board

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 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 Treasurer is a qualified Chartered Company Secretary.

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

The Charity is currently 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.

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 chylomicronemia 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;

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)

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

In the period to 31 December 2022, the trustees have had regard to the guidance issued by the Charity Commission at all times.

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 promote awareness of the condition.

The Charity seeks to support research working alongside Pharmaceutical organisations and other organisations with vested interests in bringing potential new drugs to the market for the treatment of FCS and associated conditions.

During 2022 activities were greatly curtailed due to Covid 19, however we continued to manage the facebook group FCS Community, ran the annual FCS Awareness Day,

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

For the period, expenses amounted to £397.57 whilst income totalled £281.25. Cash in Bank (reserves) totalled **£29,972.66** as at 31 December 2022.

During 2022 activities continued to be curtailed due to Covid 19, however we continued to manage the Facebook group FCS Community, ran the annual FCS Awareness Day, and recruited a new trustee to the charity.

Section E Financial review

Brief statement of the charity's policy on reserves

Details of any funds materially in deficit

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.

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)	<i>P Wade</i>	
Full name(s)	PATRICIA	WADE
Position (eg Secretary, Chair, etc)	TREASURER	
Date	4/10/2023	



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name Action FCS	No (if any) 1165873
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Receipts and payments accounts


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For the period from	Period start date 1012022	To	Period end date 31122022
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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					
Donations	281	-	-	281	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	281	-	-	281	1,857
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	281	-	-	281	1,857
A3 Payments					
Membership Subscriptions	38	-	-	38	-
Conferences/meetings/consultancy	50	-	-	50	-
Telephone/mobile	72	-	-	72	-
Office equipment	73	-	-	73	-
Insurance	165	-	-	165	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	398	-	-	398	3,700
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	398	-	-	398	3,700
Net of receipts/(payments)	- 117	-	-	- 117	- 1,843
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	30,089	-	-	30,089	31,932
Cash funds this year end	29,973	-	-	29,973	30,089

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	Lloyds Bank	29,973	-	-
		-	-	-
		-	-	-
	Total cash funds	29,973	-	-
	(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)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
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
			P A WADE	4/10/23