



# Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day	Month	Year		Day	Month	Year
	01	01	2021		31	12	2021

## 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			
4	Pat Wade	Treasurer		
5	Finian Nicholas Patrick Day-Lewis		Appointed 1 November 2021	
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7				
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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, BXL ILT	

### 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 (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 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;
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)**

In the period to 31 December 2020, 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 2021 activities were greatly 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.

**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 £3,700 whilst income totalled £1,857. Cash in Bank (reserves) totalled £30,089 as at 31 December 2021.

During 2021 activities were greatly 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)

*Patricia Anne Wade*

Full name(s)

PATRICIA ANNE WADE

Position (eg Secretary, Chair, etc)

TREASURER

Date

14/09/2022



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name <b>Action FCS</b>	No (if any) 1186873
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## Receipts and payments accounts

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For the period from	Period start date 01/01/2021	To	Period end date 31/12/2021
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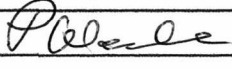
### Section A Receipts and payments

	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 £
<b>A1 Receipts</b>					
Conferences/meetings/consultancy	750	-	-	750	-
Donations	1,107	-	-	1,107	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>1,857</b>	<b>-</b>	<b>-</b>	<b>1,857</b>	<b>2,963</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>1,857</b>	<b>-</b>	<b>-</b>	<b>1,857</b>	<b>2,963</b>
<b>A3 Payments</b>					
Membership Subscriptions	88	-	-	88	-
Conferences/meetings/consultancy	887	-	-	887	-
Telephone/mobile	60	-	-	60	-
Website	2,500	-	-	2,500	-
Insurance	165	-	-	165	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>3,700</b>	<b>-</b>	<b>-</b>	<b>3,700</b>	<b>672</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>1,478</b>
<b>Total payments</b>	<b>3,700</b>	<b>-</b>	<b>-</b>	<b>3,700</b>	<b>2,150</b>
<b>Net of receipts/(payments)</b>	<b>- 1,843</b>	<b>-</b>	<b>-</b>	<b>- 1,843</b>	<b>813</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>31,932</b>	<b>31,119</b>
<b>Cash funds this year end</b>	<b>30,089</b>	<b>-</b>	<b>-</b>	<b>30,089</b>	<b>31,932</b>

## 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 £
<b>B1 Cash funds</b>	Lloyds Bank	30,089	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>30,089</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>			Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>		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	14/9/22