

Trustees' Annual Report for the period

		Period start date			Period end date		
From	Day	Month	Year	To	Day	Month	Year
	01	01	2020		31	12	2020

Section A Reference and administration details

Charity name	Action FCS
Other names charity is known by	LPLD Alliance
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		

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, BXI 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.

The Charity remains reliant solely on the volunteer board to achieve its objectives with key man dependencies recognised. The Board is developing its risk framework and strategies.

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

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 has continued to work towards its aims and objectives. We changed our name to Action FCS in recognition to incorporate all patients with Familial Chylomicronaemia Syndrome and launched our new website with the new logo. We ran a series of online patient meetings including a dietitian-led information session on the FCS diet, and held our annual FCS Awareness Day.

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)

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.

Summary of the main achievements of the charity during the year

For the period, expenses amounted to £2,150 whilst income totalled £2,963. Net receipts were therefore £813. Cash in Bank (reserves) totalled £31,932 as at 31 December 2020.

Our main achievements this year were to change our name, launch our new website and to run a series of online patient meetings including a dietitian-led information event.

Section E Financial review

Brief statement of the charity's policy on reserves

The charity aims to apply income towards its objectives maintaining a level of reserves to meet liabilities; for example, in respect of ongoing website maintenance costs. The balance in reserves arises from the emphasis and time spent on creating a solid foundation and identity for the charity in its early days, including the growth in networks of people affected by FCS.

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.

As referred to above, 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. The Charity has worked closely with such pharmaceutical organisations, as this aligns with one of the key objectives of the Charity to advocate for access to excellent care and new medicines for all patients with FCS.

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 Wade

Full name(s)

PATRICIA WADE

Position (eg Secretary, Chair, etc)

Treasurer

Date

11 October 2021



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name No (if any)

Receipts and payments accounts

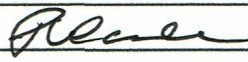
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For the period from	Period start date 01/01/2020	To	Period end date 31/12/2020
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Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	20	-	-	20	-
Conferences/meetings/consultancy	2,938	-	-	2,938	-
Sundry	5	-	-	5	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	2,963	-	-	2,963	3,941
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	2,963	-	-	2,963	3,941
A3 Payments					
Membership Subscriptions	38	-	-	38	-
Conferences/meetings/consultancy	108	-	-	108	-
Website and marketing	362	-	-	362	-
Insurance	165	-	-	165	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	672	-	-	672	4,602
A4 Asset and investment purchases, (see table)					
new PC	1,478	-	-	1,478	-
	-	-	-	-	-
Sub total	1,478	-	-	1,478	-
Total payments	2,150	-	-	2,150	4,602
Net of receipts/(payments)	813	-	-	813	661
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	31,119	31,779
Cash funds this year end	813	-	-	31,932	31,119

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 A/c	31,932	-	-
		-	-	-
		-	-	-
	Total cash funds	31,932	-	-
	(agree balances with receipts and payments account(s))			
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
	Computers, one pc and one printer	Unrestricted	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities		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	11/10/21	