

# Action FCS

England & Wales · Charity number 1165873

## Details

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Other names	LPLD ALLIANCE
Status	Registered
Legal form	CIO
Registered	2016-03-04
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Address	36 Gaskell Street London SW4 6NS
Phone	07920715366
Email	<a href="mailto:info@actionfcs.org">info@actionfcs.org</a>
Website	<a href="http://www.actionfcs.org">www.actionfcs.org</a>

## Activities

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**Objects:** THE OBJECTS OF THE CIO ARE TO RELIEVE SICKNESS AND PRESERVE AND PROTECT GOOD HEALTH OF PERSONS SUFFERING FROM FAMILIAL LIPOPROTEIN LIPASE DEFICIENCY (LPLD) AND RELATED CONDITIONS BY: 1. RAISING AWARENESS OF LPLD AND RELATED CONDITIONS; 2. EDUCATING PATIENTS, MEDICAL PERSONNEL AND THE PUBLIC IN GENERAL ABOUT LPLD; 3. SUPPORTING PEOPLE WITH LPLD AND THOSE AFFECTED BY IT TO LIVE A FULL, HEALTHY AND INTEGRATED LIFE; 4. ADVOCATING FOR ACCESS TO EXCELLENT CARE AND NEW MEDICINES FOR ALL PATIENTS WITH LPLD. NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CIO FOR THE PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH SECTION 7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) ACT 2005 AND SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008.

**Activities:** Raising awareness of Familial Chylomicronaemia Syndrome (FCS) and related conditions; educating patients, medical personnel and the public in general about FCS; 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.

## Classification

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- **How:** Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

## Geography

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- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2024-12-31	£200	£415	-	-
2023-12-31	£339	£787	-	-
2022-12-31	£281	£398	-	-
2021-12-31	£1,857	£3,700	-	-
2020-12-31	£2,963	£2,150	-	-

## Trustees

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Name	Role	Appointed
JILL PRAWER	Chair	2016-02-22
Finion Nicholas Patrick Day-Lewis		2021-11-01
Helen Olufunke Aderin		2018-03-06
Helga Davidson		2025-04-18
Mrs Pat Wade		2017-12-04

**Action FCS**

England & Wales - Charity number 1165873

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# Accounts

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## 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	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's organisational structure and any wider network with which the charity works	Para 1.51	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.
Relationship with any related parties	Para 1.51	
Other		



## 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

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	



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Action FCS 1165873

## Receipts and payments accounts

CC16a

For the period from 10/12/2024 To 31/12/2024

### 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>	<b>200</b>	<b>-</b>	<b>-</b>	<b>200</b>	<b>338</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>200</b>	<b>-</b>	<b>-</b>	<b>200</b>	<b>338</b>
<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>	<b>415</b>	<b>-</b>	<b>-</b>	<b>415</b>	<b>787</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>415</b>	<b>-</b>	<b>-</b>	<b>415</b>	<b>787</b>
<b>Net of receipts/(payments)</b>	<b>- 215</b>	<b>-</b>	<b>-</b>	<b>- 215</b>	<b>- 449</b>
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	29,524	-	-	29,524	29,973
<b>Cash funds this year end</b>	<b>29,309</b>	<b>-</b>	<b>-</b>	<b>29,309</b>	<b>29,524</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>		-	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>29,309</b>	-	-
	<small>(agree balances with receipts and payments account(s))</small>			

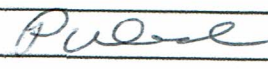
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	PATRICIA NADIN	17/9/25

**Action FCS**

England & Wales - Charity number 1165873

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# Accounts

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## 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 2023, 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		

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## 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, 524. Receipts during the year totalled £339, whilst payments amounted to £787, showing a small net deficit for 2023 of £448.
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.
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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		

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## 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	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's organisational structure and any wider network with which the charity works	Para 1.51	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.
Relationship with any related parties	Para 1.51	
Other		

### Reference and Administrative details

Charity name	Action FCS
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## 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

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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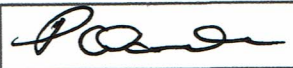
## Other optional information

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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)	Secretary	

Date 12 September 2024



CHARITY COMMISSION  
FOR ENGLAND AND WALES

ActionFCS

No (if any)  
4165873

## Receipts and payments accounts

CC16a

For the period from	1012020	To	31122023
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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>					
Donations	225	-	-	225	-
Confereance , consultancy meetings	100	-	-	100	-
Sundry refund	14	-	-	14	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>339</b>	<b>-</b>	<b>-</b>	<b>339</b>	<b>281</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>339</b>	<b>-</b>	<b>-</b>	<b>339</b>	<b>281</b>
<b>A3 Payments</b>					
Membership and Regulation Subscriptions	88	-	-	88	-
Mobile	60	-	-	60	-
IT	474	-	-	474	-
Insurance	165	-	-	165	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>787</b>	<b>-</b>	<b>-</b>	<b>787</b>	<b>398</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>787</b>	<b>-</b>	<b>-</b>	<b>787</b>	<b>398</b>
<b>Net of receipts/(payments)</b>	<b>- 448</b>	<b>-</b>	<b>-</b>	<b>- 448</b>	<b>- 117</b>
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	29,973	-	-	29,973	-
<b>Cash funds this year end</b>	<b>29,524</b>	<b>-</b>	<b>-</b>	<b>29,524</b>	<b>- 117</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	29,524	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>29,524</b>	<b>-</b>	<b>-</b>
(agree balances with receipts and payments account(s))				

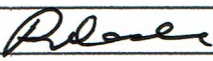
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	Patricia Wade	12/9/24

**Action FCS**

England & Wales - Charity number 1165873

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# Accounts

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# Trustees' Annual Report for the period

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

## Section A                      Reference and administration details

Charity name

Other names charity is known by

Registered charity number (if any)

Charity's principal address

Postcode

### 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, 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	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;

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,

**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.

**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**

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



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name  
**Action FCS**

No (if any)  
1165873

**CC16a**

**Receipts and payments accounts**

For the period from **1012022** To **31122022**

**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>					
Donations	281	-	-	281	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>281</b>	<b>-</b>	<b>-</b>	<b>281</b>	<b>1,857</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>281</b>	<b>-</b>	<b>-</b>	<b>281</b>	<b>1,857</b>
<b>A3 Payments</b>					
Membership Subscriptions	38	-	-	38	-
Conferences/meetings/consultancy	50	-	-	50	-
Telephone?mobile	72	-	-	72	-
Office equipment	73	-	-	73	-
Insurance	165	-	-	165	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>398</b>	<b>-</b>	<b>-</b>	<b>398</b>	<b>3,700</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>398</b>	<b>-</b>	<b>-</b>	<b>398</b>	<b>3,700</b>
<b>Net of receipts/(payments)</b>	<b>- 117</b>	<b>-</b>	<b>-</b>	<b>- 117</b>	<b>- 1,843</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>30,089</b>	<b>-</b>	<b>-</b>	<b>30,089</b>	<b>31,932</b>
<b>Cash funds this year end</b>	<b>29,973</b>	<b>-</b>	<b>-</b>	<b>29,973</b>	<b>30,089</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	29,973	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>29,973</b>	<b>-</b>	<b>-</b>

(agree balances with receipts and payments account(s))

OK

OK

OK

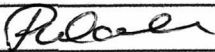
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	P A WADE	4/10/23

**Action FCS**

England & Wales - Charity number 1165873

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# Accounts

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# Trustees' Annual Report for the period

<b>From</b>	Period start date			<b>To</b>	Period end date		
	Day 01	Month 01	Year 2021		Day 31	Month 12	Year 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 Praver	Chair		
2	Helen Aderin			
3	Catherine Brun			
4	Pat Wade	Treasurer		
5	Finian Nicholas Patrick Day-Lewis		Appointed 1 November 2021	
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, 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 <i>(eg. trust deed, constitution)</i>	Constitution
How the charity is constituted <i>(eg. trust, association, company)</i>	Charitable Incorporated Organisation
Trustee selection methods <i>(eg. appointed by, elected by)</i>	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.

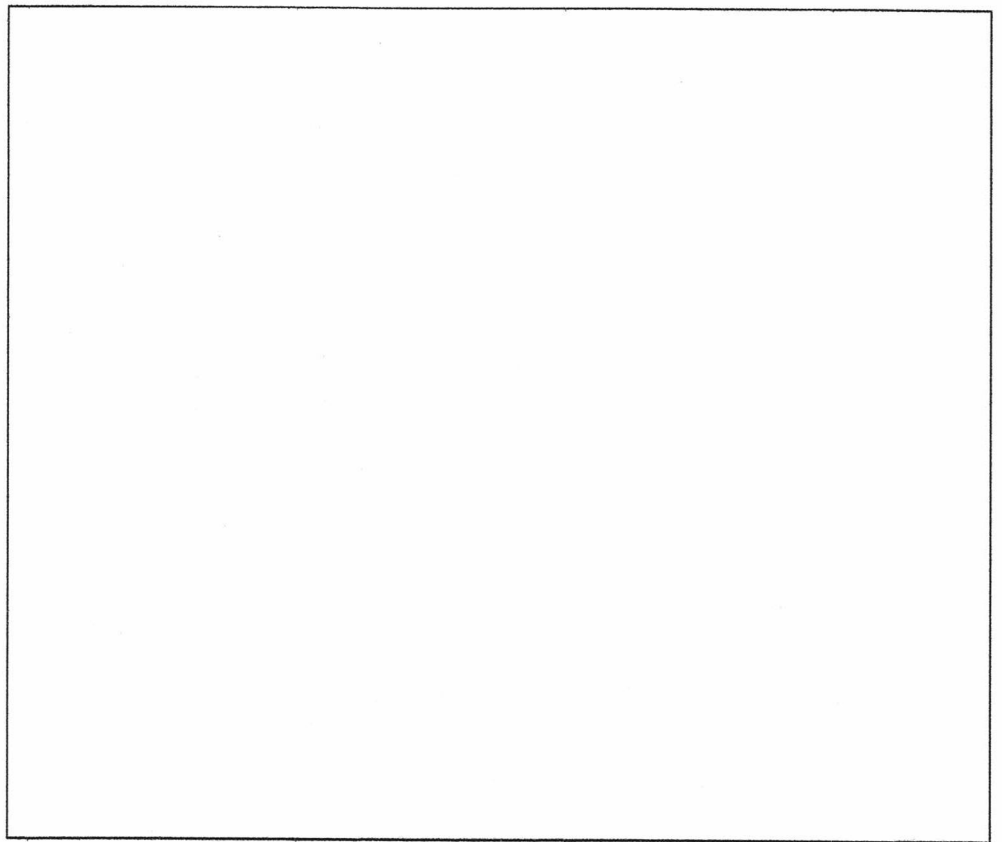
The Charity seeks to support research working alongside Pharmaceutical organisations and other organisations with vested interests in bringing potential new drugs to the market for the treatment of FCS and associated conditions.

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

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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.

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## Section F

## Other optional information

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## 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>PA Wade</i>	
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Full name(s)

PATRICIA ANNE WADE	
--------------------	--

Position (eg Secretary, Chair, etc)

TREASURER	
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Date

14/09/2022
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CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name <b>Action FCS</b>	No (if any) 1186873
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**CC16a**

**Receipts and payments accounts**

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>31,932</b>	<b>31,119</b>
<b>A6 Cash funds last year end</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>30,089</b>	<b>31,932</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

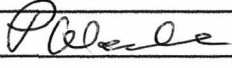
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	PATRICIA WADE	14/9/22

**Action FCS**

England & Wales - Charity number 1165873

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# Accounts

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# Trustees' Annual Report for the period

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

**From**

**To**

## 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)

## 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)
--------------	-------------

CC16a

## Receipts and payments accounts

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 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>					
Donations	20	-	-	20	-
Conferences/meetings/consultancy	2,938	-	-	2,938	-
Sundry	5	-	-	5	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>2,963</b>	<b>-</b>	<b>-</b>	<b>2,963</b>	<b>3,941</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>2,963</b>	<b>-</b>	<b>-</b>	<b>2,963</b>	<b>3,941</b>
<b>A3 Payments</b>					
Membership Subscriptions	38	-	-	38	-
Conferences/meetings/consultancy	108	-	-	108	-
Website and marketing	362	-	-	362	-
Insurance	165	-	-	165	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>672</b>	<b>-</b>	<b>-</b>	<b>672</b>	<b>4,602</b>
<b>A4 Asset and investment purchases, (see table)</b>					
new PC	1,478	-	-	1,478	-
	-	-	-	-	-
<b>Sub total</b>	<b>1,478</b>	<b>-</b>	<b>-</b>	<b>1,478</b>	<b>-</b>
<b>Total payments</b>	<b>2,150</b>	<b>-</b>	<b>-</b>	<b>2,150</b>	<b>4,602</b>
<b>Net of receipts/(payments)</b>	<b>813</b>	<b>-</b>	<b>-</b>	<b>813</b>	<b>661</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>31,119</b>	<b>31,779</b>
<b>Cash funds this year end</b>	<b>813</b>	<b>-</b>	<b>-</b>	<b>31,932</b>	<b>31,119</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 A/c	31,932	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>31,932</b>	<b>-</b>	<b>-</b>
(agree balances with receipts and payments account(s))				

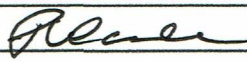
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>	Computers, one pc and one printer	Unrestricted	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	PATRICIA WADE	11/10/21