

CYSTINOSIS FOUNDATION OF THE UK

England & Wales - Charity number 1074885

Details

Other names	CYSTINOSIS FOUNDATION - UK AND EIRE, CYSTINOSIS SUPPORT FOUNDATION OF THE UK AND EIRE
Status	Registered
Legal form	Other
Registered	1999-03-26
Register	View on the Charity Commission register

Contact

Address Cystinosis Foundation UK
Unit 81304
PO Box 15113
Birmingham
B2 2NJ

Phone 07976272064

Email advice@cystinosis.org.uk

Website www.cystinosis.org.uk

Activities

Objects: TO RELIEVE PERSONS SUFFERING FROM CYSTINOSIS AND MEMBERS OF THEIR IMMEDIATE FAMILIES WHO ARE NECESSITOUS CIRCUMSTANCES IN PARTICULAR BY THE PROVISION OF INFORMATION AND FINANCIAL SUPPORT AND BY RAISING PUBLIC AWARENESS OF THE DISORDER.

Activities: To provide support to anyone diagnosed with cystinosis, as well as their families and friends. To highlight the disorder to members, the medical profession and the wider community. To assist in the promotion of research into the treatment of cystinosis. To work alongside other similar organisations in understanding more about metabolic disorders in general

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, People With Disabilities, Other Defined Groups

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£34,431	£19,238	-	-
2024-03-31	£21,084	£16,033	-	-
2023-03-31	£45,281	£115,891	-	-
2022-03-31	£21,443	£5,664	-	-
2021-03-31	£20,278	£10,844	-	-

Trustees

Name	Role	Appointed
William George Newman	Chair	2020-02-23
Alexandra Innes Hutchison		2020-02-23
Bradley Pearson		2026-03-18
David Nigel Benford		
Karthikeyan Ekambaram		2020-02-23
Kirsty Avril Biss		2025-03-25
Thomas Ian Kenning		2014-02-23
Thomas Stuart-Black Kelly		2025-03-25

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For the year ended 31 March 2025

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**Financial Statements for the year ended
31 March 2025**

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CYSTINOSIS FOUNDATION OF THE UK

Treasurer's Report for the year ended 31 March 2025

The year ending 31 March 2025 has seen an increase in fundraising income compared to last year, mainly due to a couple of planned events by supporters, although as Will Newman mentions in the Trustees Report, there seems to be a general slow down in donations.

This year has seen the CNE International Conference being held in Manchester resulting in higher than usual expenditure. That being said, Net Income is still up 64% on last year.

We remain especially grateful to all the friends of Cystinosis who continue and devote considerable time to raising the profile of the Charity and to raising the very valuable funds.

We confirm that there are no serious incidents or other matters relating to our charity, over the financial year ended 31 March 2025 that should have been reported to the Charity Commission but have not. For clarification, serious incidents are defined as events that have caused or could cause harm to our charity.

Anne-Marie Sugden
Treasurer

CYSTINOSIS FOUNDATION OF THE UK

Trustee's Report for the year ended 31 March 2025

Cystinosis Foundation UK aims to:

Improve: patient outcomes, treatments and research.

Inform: patients, families and healthcare professionals.

Share: stories, experiences and answers.

CF10 Drug Development (Major ongoing priority)

The foundation is heavily invested in CF10, a new treatment being developed at Sunderland/Durham University. Over the period, the project progressed from early purity issues to securing £4.2m MRC grant application (decision expected June 2025). Phase 1 trial planned to start September 2026 if funded. The foundation agreed to fund the £48k PALS (Pharmacology and Logistics Study) at the May 2025 meeting.

CNE International Conference July 2024

The foundation hosted a highly successful international conference with excellent feedback from clinicians, families, and patients. Key successes included the high-quality speakers, and strong interaction between clinicians, scientists, and families. It was good to see so many of the UK families able to attend. A new adult WhatsApp group with 27 members formed after the event. Conference videos were edited and posted to YouTube.

Procysbi

Ongoing efforts to secure NHS funding for Procysbi treatment in England and Scotland. The NICE process for NHS England funding was ongoing, with positive clinical panel response recommending routine commissioning. Despite previous setbacks, there are still hopes that an application to the Scottish Medicines Consortium can prove successful.

Trustee Changes

Neil Sugden retired after years of service. Two new trustees joined: Tom Kelly and Avril Biss (introduced November 2024, formally appointed early 2025). The foundation will need to find a new treasurer as Anne-Marie Sugden is also retiring. Banking signatories are to be updated accordingly.

Operational Developments

- Website redesign needed and in progress
- Newsletter published regularly with trustee contributions
- Social media presence needs strengthening
- NatWest Bankline subscription approved (£20/month)

Clinical Relationships

Strong partnerships developed with Clinical Nurse Specialists across hospital hubs, with regular cross-hub meetings showing improvement. The foundation attended annual hub meetings and CNS meetings, providing patient perspective. Recordati (pharmaceutical company) selected CFUK as charity of the year and is working on improving eye treatment products based on patient feedback.

Financial Position

As of February 2025, the foundation had £218,627 in the bank. Major fundraising included £4,000+ from London Marathon runner. The foundation is concerned about declining JustGiving donations and agreed to be more active in promoting fundraising on social media.

We are grateful for the all support we have received from developing partnerships and from the cystinosis community. Fund raisers and awareness raisers are doing a fantastic job to ensure that the charity can continue to improve and inform and share.

Will Newman

On behalf of the Trustees

CYSTINOSIS FOUNDATION OF THE UK

INFORMATION

Name	Cystinosis Foundation of the UK
Charity Registration Number	1074885
Address of the Principal Office	Unit 81304 PO Box 15113 Birmingham B2 2NJ
Trustees	Will Newman (Chair) David Benford Tom Kenning Alex Hutchison Karthik Ekambaram Kirsty Biss Thomas Kelly
Trust Deed	Dated 2 February 1998
Objectives	To provide support, education, research support and co-operation to Cystinosis sufferers and their immediate families.

CYSTINOSIS FOUNDATION OF THE UK

INCOME AND EXPENDITURE ACCOUNT **FOR THE YEAR ENDED 31 MARCH 2025**

<u>INCOME</u>	<u>2025</u>	<u>2024</u>
Personal Donations	3,465.00	3,505.00
Corporate Donations	6,392.93	0.00
Fund Raising	24,573.31	16,496.66
Bank Interest	0.00	1,081.99
Tax Repayments	0.00	0.00
	<u>34,431.24</u>	<u>21,083.65</u>
<u>EXPENDITURE</u>		
Membership fees	50.00	50.00
Travelling and Conferences	16,406.00	10,592.28
Telephone	92.60	0.00
Office & Fundraising Expenses	2,689.08	1,157.50
	<u>19,237.68</u>	<u>11,799.78</u>
<u>NET INCOME</u>	<u>15,193.56</u>	<u>9,283.87</u>
TRUSTEES EQUITY brought forward	207,022.98	201,972.20
CAPITAL DISTRIBUTIONS (see notes)	0.00	4,233.09
TRUSTEES EQUITY carried forward	<u>222,216.54</u>	<u>207,022.98</u>

CYSTINOSIS FOUNDATION OF THE UK

BALANCE SHEET FOR YEAR TO 31 MARCH 2025

	<u>2025</u>	<u>2024</u>
<u>CURRENT ASSETS</u>		
Cash at Bank	222,216.54	207,022.98
<u>DEBTORS</u>	0.00	0.00
	<u>222,216.54</u>	<u>207,022.98</u>
 CREDITORS	 0.00	 0.00
 <u>NET ASSETS</u>	 <u>222,216.54</u>	 <u>207,022.98</u>
 Represented by:-		
 TRUSTEES EQUITY	 <u>222,216.54</u>	 <u>207,022.98</u>



Chairman



Treasurer

CYSTINOSIS FOUNDATION OF THE UK

Notes to The Accounts dated 31 March 2025

Funds Specifically Allocated for Research

The University of Sunderland

The Trustees have continued to provide financial support for the research being carried out at the University of Sunderland.

UK Conference

The Trustees have contributed £14,200 towards the Cystinosis UK Conference during the financial year

No funds were specifically allocated at the year-end beyond what is presented in these financial statements.

Reserve Policy

Future commitments are only entered into once fund raising has covered the obligations.

Independent examiners report to the trustees of Cystinosis Foundation of the UK

I report to the trustees on my examination of the accounts of the Cystinosis Foundation of the UK for the year ended 31st March 2025.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent Examiners Statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect;

1. Accounting records were not kept in respect of the Trust as required by section 130 of the Act;
or
2. The accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable proper understanding of the accounts to be reached.

Signed:



Name: Louisa Poole

Date: 02/02/2026

2025 Accounts Final-combined (1)

Final Audit Report

2026-02-02

Created:	2026-02-02
By:	Anne-Marie Sugden (a.sugden@harlowbros.co.uk)
Status:	Signed
Transaction ID:	CBJCHBCAABAAaZ7J3SVAniEZlrle_Q2-Aq-xee3IH6X3

"2025 Accounts Final-combined (1)" History

-  Document created by Anne-Marie Sugden (a.sugden@harlowbros.co.uk)
2026-02-02 - 1:43:36 PM GMT
-  Document emailed to Will Newman (will@cystinosis.org.uk) for signature
2026-02-02 - 1:43:41 PM GMT
-  Email viewed by Will Newman (will@cystinosis.org.uk)
2026-02-02 - 3:28:20 PM GMT
-  Document e-signed by Will Newman (will@cystinosis.org.uk)
Signature Date: 2026-02-02 - 3:31:58 PM GMT - Time Source: server
-  Agreement completed.
2026-02-02 - 3:31:58 PM GMT

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Treasurer's Report for the year ended 31 March 2023

The year ending 31 March 2023 has seen an increase in fundraising compared the the last couple of years. The charity received a generous donation of £16,000 from the organisers of a big birthday bash barn dance, plus we were awarded a grant of £10,600 from COPADI Ltd

The ongoing reduction in administrative costs has resulted in the charity reporting a net income of £43.6k, an increase of 176% comaped to last year.

We remain especially grateful to all the friends of Cystinosis who continue and devote considerable time to raising the profile of the Charity and to raising the very valuable funds.

We confirm that there are no serious incidents or other matters relating to our charity, over the financial year ended 31 March 2023 that should have been reported to the Charity Commission but have not. For clarification, serious incidents are defined as events that have caused or could cause harm to our charity.

Anne-Marie Sugden
Treasurer

CYSTINOSIS FOUNDATION OF THE UK

Trustee's Report for the year ended 31 March 2023

Cystinosis Foundation UK aims to:

Improve: patient outcomes, treatments and research.

Inform: patients, families and healthcare professionals.

Share: stories, experiences and answers.

Research

The trustees continue to work with the CF10 project team to progress towards clinical trials. They have worked to improve the protocol for the PALs project and the single dose in-person study. We are grateful to Sunderland University who have agreed to fund the single dose study. Initial reports from the 2 joint funded projects with Cystinosis Ireland (cystinosis muscles and contact lens delivery of cysteamine) have been very positive.

Treatment

The new Cystinosis specialist hubs have been announced in Manchester, Birmingham and London and they are expected to help improve the standard of care and also support earlier diagnosis. Recordati are planning an Advisory Board with clinicians from the hubs and a CFUK trustee will attend this meeting to ensure the patient voice is represented.

Medication

Patients in England are now able to access Cystadrops but it is important that the pharmacy produced drops are still available for Wales, Scotland and Northern Ireland and also for those who choose to use them in England. A successful submission was made for Procysbi to be routinely prescribed in Wales. A resubmission in Scotland is also underway with CFUK working with Metabolic Support UK and Kidney Research UK.

CNE Conference

Our chair attended the 2022 Conference in Belgium, the first in person conference after the Covid pandemic, so many people were still reluctant to travel. Using this experience the trustees have decided to bid to hold the 2024 International conference in the UK.

Newsletter

CFUK will produce a new quarterly email newsletter to share stories, encourage fundraising and involve the community. People will be able to sign up via the website.

Finally, as ever, we are indebted to all those who have helped raise funds to support the work we do. To those who have set up standing orders, run marathons, dived through mud or organised coffee mornings we thank you all.

Will Newman
On behalf of the Trustees

CYSTINOSIS FOUNDATION OF THE UK

INFORMATION

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CYSTINOSIS FOUNDATION OF THE UK

INCOME AND EXPENDITURE ACCOUNT **FOR THE YEAR ENDED 31 MARCH 2023**

<u>INCOME</u>	<u>2023</u>	<u>2022</u>
Personal Donations	2,835.28	3,036.00
Corporate Donations	10,600.00	0.00
Fund Raising	31,845.72	18,407.30
Bank Interest	0.00	0.00
Tax Repayments	0.00	0.00
	<u>45,281.00</u>	<u>21,443.30</u>
<u>EXPENDITURE</u>		
Membership fees	50.00	0.00
Travelling and Conferences	0.00	0.00
Telephone	0.00	0.00
Office & Fundraising Expenses	1,611.43	5,663.66
	<u>1,661.43</u>	<u>5,663.66</u>
<u>NET INCOME</u>	<u>43,619.57</u>	<u>15,779.64</u>
TRUSTEES EQUITY brought forward	272,582.04	256,802.40
CAPITAL DISTRIBUTIONS (see notes)	114,229.41	0.00
TRUSTEES EQUITY carried forward	<u>201,972.20</u>	<u>272,582.04</u>

CYSTINOSIS FOUNDATION OF THE UK

BALANCE SHEET FOR YEAR TO 31 MARCH 2023

	<u>2023</u>	<u>2022</u>
<u>CURRENT ASSETS</u>		
Cash at Bank	201,972.20	272,582.04
<u>DEBTORS</u>	0.00	0.00
	<u>201,972.20</u>	<u>272,582.04</u>
CREDITORS	0.00	0.00
<u>NET ASSETS</u>	<u>201,972.20</u>	<u>272,582.04</u>
Represented by:-		
TRUSTEES EQUITY	<u>201,972.20</u>	<u>272,582.04</u>

Chairman

Treasurer

CYSTINOSIS FOUNDATION OF THE UK

Notes to The Accounts dated 31 March 2023

Funds Specifically Allocated for Research

The University of Sunderland

The Trustees have continued to provide financial support for the research being carried out at the University of Sunderland.

Colorado School of Mines

The Trustees have contributed £60,844 in support of the Contact Lens Research being carried out

Ku Leven

The Trustees have provided financial support of £43,385 towards the research being carried out into Muscle Wasting

Ku Leven

The Trustees have contributed £10,000 towards the Cystinosis International Conference during the financial year

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Reserve Policy

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Independent examiners report to the trustees of Cystinosis Foundation of the UK

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1. Accounting records were not kept in respect of the Trust as required by section 130 of the Act;
or
2. The accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable proper understanding of the accounts to be reached.

Signed:



Name: Louisa Poole, FCA
ICAEW

Date: 29th May 2024