

# **CYSTINOSIS FOUNDATION OF THE UK**

Charity Registration Number 1074885

## **ACCOUNTS**

**For the year ended 31 March 2025**

# **CYSTINOSIS FOUNDATION OF THE UK**

**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**

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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**

<b><u>INCOME</u></b>	<b><u>2025</u></b>	<b><u>2024</u></b>
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>
<b><u>EXPENDITURE</u></b>		
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>
<b><u>NET INCOME</u></b>	<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
<b>TRUSTEES EQUITY</b> 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 31<sup>st</sup> 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

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