

# **CYSTINOSIS FOUNDATION OF THE UK**

Charity Registration Number 1074885

## **ACCOUNTS**

**For the year ended 31 March 2023**

# **CYSTINOSIS FOUNDATION OF THE UK**

**Financial Statements for the year ended  
31 March 2023**

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## **CYSTINOSIS FOUNDATION OF THE UK**

### **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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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 Neil Sugden Alex Hutchison Karthik Ekambaram
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 2023**

<b><u>INCOME</u></b>	<b><u>2023</u></b>	<b><u>2022</u></b>
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>
 <b><u>EXPENDITURE</u></b>		
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>
 <b><u>NET INCOME</u></b>	<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>	<u>0.00</u>	<u>0.00</u>
	201,972.20	272,582.04
 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

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 2023.

### **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, FCA  
ICAEW

Date: 29th May 2024