



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 1st January 2023 **Period start date** **To** 31st December 2023
Period end date

Charity name: Cure CLCN4 LTD

Charity registration number: 1190344

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	Cure CLCN4 Limited is a not-for-profit organisation constituted with charitable purposes in perpetuity. The company is limited by guarantee and is governed by a memorandum and articles of association. The objectives of Cure CLCN4 Limited are: a) The advancement of health, relief of sickness and saving of lives by such means as the trustees see fit including but not exclusively through: i) Providing relief and assistance to people suffering from pathogenic variants of clcn4; and ii) The funding of medical research anywhere in the world for the purpose of discovering, developing and delivering treatment for patients with pathogenic variants of clcn4; and B) The furtherance of such other charitable purpose or charitable purposes as the trustees in their absolute discretion from time-to-time think fit, in each case for the public benefit.
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	The Charity's objects are such exclusively charitable objects and purposes for the public benefit throughout England and Wales as the trustees may in their discretion think fit. The Charity furthers its charitable purposes for the benefit of the public by funding or undertaking scientific research for the advancement of knowledge of Clcn4 related condition and by supporting those affected by it.
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees have due regard to the Charity Commission's guidance as to operation of the public benefit requirement when exercising powers or duties to which the guidance is relevant and in their opinion the charity's activities are wholly for the benefit of the public.

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	Para 1.38	

including program related investment		
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	Cure CLCN4 LTD has successfully funded the generation of important tools for the furthering of scientific research into CLCN4 condition (specifically three rat models of CLCN4-related condition) and supported the expansion of the CLCN4 online patient registry (hosted by Simons Searchlight) We have worked on supporting affected families via the provision of accessible and up-to-date information on CLCN4 condition. Further we organised the second Cure CLCN4 Scientific Meeting, which took place in London, and successfully brought together the scientific and clinical community for two days of talks and discussions on CLCN4-condition. The conference also engaged early-career researchers via a poster session.

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	The charity's financial position at the end of 2023 is healthy with a balance of 3,671GBP. This is the third year that the charity has an income. This revenue has allowed us to support the charity's projects in the furtherance of our objectives including research and support of affected families.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The trustees aim to maintain reserves at a level which equates to approximately six months of charitable expenditure. The trustees consider that this level will provide sufficient funds for operational needs and ensure that support and governance costs are covered. The trustees consider that a level of 5-6 months is sufficient. Although the reserves at 31 December 2023 fell below the level desired by the trustees this will be replenished in early 2024 by a cash donation from Peter Trill, a charity trustee.
Amount of reserves held	Para 1.22	3,671GBP
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	No uncertainties.

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	
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	
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed , royal charter)	Para 1.25	Memorandum and Articles Incorporated 06 Feb 2020
How is the charity constituted? (e.g unincorporated association , CIO)	Para 1.25	Charitable company (limited by guarantee)
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	The Board shall be permitted to appoint by majority decision any individual who is eligible as a Trustee to fill a vacancy in their number or as an additional Trustee.

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

Reference and Administrative details

Charity name	Cure CLCN4 LTD
Other name the charity uses	
Registered charity number	1190344
Charity's principal address	2 Duke Street London W1U 3EH

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	Peter James Alistair Trill			
2	Larry Louison			
3	Alan Wise			
4	Wang Sin Tan			
5	Alexis Karim			
6	Paul McGuinness			
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Corporate trustees – names of the directors at the date the report was approved

Director name		
Peter James Alistair Trill		
Larry Louison		
Alan Wise		
Wang Sin Tan		
Alexis Karim		
Paul McGuinness		

Name of trustees holding title to property belonging to the charity

[illegible]

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	N/A
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

Additional information (optional)

Names and addresses of advisers (Optional information)

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)	Peter James Alistair Trill	
Position (eg Secretary, Chair, etc)	Trustee, Chair	
Date	10/02/2024	

CURE CLCN4
(a company limited by guarantee)

Financial Statements
for the period ended
31 December 2023

Company Number: 12447230

CURE CLCN4 (a company limited by guarantee)

Statement of accounts for the period ended 31 December 2023

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CURE CLCN4 (a company limited by guarantee)

Legal and administrative information

Governed by

Memorandum and Articles of Association dated 6 February 2020.

Directors

P Trill
A Karim
W Tan
A Wise
L Louison
Paul McGuinness

Registered Office

2 Duke Street
London
W1U 3EH

Accountants

TC Group
6th Floor, Kings House
9-10 Haymarket
London
United Kingdom
SW1Y 4BP

Registered charity number

1190344

Company Number

12447230

CURE CLCN4 (a company limited by guarantee)

Directors' Report

The Directors' submit the organisations report for the period ended 31 December 2023.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The organisation is a charitable company limited by guarantee. The company was established under a memorandum of Association which sets out the objects and powers of the charitable company and is governed under its Articles of Association.

Recruitment, Appointment and Training of Trustees

Trustees can be nominated by any member of the Board of the Trustees to replace a trustee stepping down.

Appointment of newly nominated Trustees requires unanimous approval of all Trustees.

The new Trustee is provided with details of Trustees' roles and responsibilities. Training as such is not provided as no one has felt it to be necessary. At meetings, there is always room for questions and explanations.

OBJECTIVES AND ACTIVITIES

Charitable Objectives

Cure CLCN4 Limited is a not for profit organisation constituted with charitable purposes in perpetuity. The company is limited by guarantee and is governed by a memorandum and articles of association.

The objectives of Cure CLCN4 Limited are:

- A) The advancement of health, relief of sickness and saving of lives by such means as the trustees see fit including but not exclusively through:
 - i) Providing relief and assistance to people suffering from pathogenic variants of clcn4; and
 - ii) The funding of medical research anywhere in the world for the purpose of discovering, developing and delivering treatment for patients with pathogenic variants of clcn4; and
- B) The furtherance of such other charitable purpose or charitable purposes as the trustees in their absolute discretion from time to time think fit, in each case for the public benefit.

FINANCIAL REVIEW

This is the fourth year of operations, and the focus has been on expanding our research activities, specifically by funding the development of key research tools, which have been made available to the research community for use in CLCN4-related condition research. Another focus has been on growing the annual scientific conference, essential to engage our scientific and clinical network. The second scientific conference was celebrated in the summer of 2023, and helped set research priorities, engage new researchers in the field and increase awareness of CLCN4-condition among the community.

CURE CLCN4 (a company limited by guarantee)

Directors' Report (continued)

STATEMENT OF DIRECTORS' RESPONSIBILITIES

The Directors' are required under company law to prepare financial statements for each financial year. Under that law the directors have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law Directors' must not approve the financial statements unless they are satisfied that they give a true and fair view of the company and of the surplus or deficit of the company for that period. In preparing those financial statements the Directors' are required to:

- a) Select suitable accounting policies and then apply them consistently;
- b) Observe the methods and principles in the Charities SORP;
- c) Make judgements and estimates that are reasonable and prudent;
- d) State whether applicable UK accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- e) Prepare the financial statements on a going concern basis unless it is inappropriate to presume that the company will continue in operation.

The Directors' are responsible for keeping adequate accounting records that are sufficient to show and explain the company's transactions and disclose with reasonable accuracy at any time the financial position of the Company and enable them to ensure that the financial statements comply with the requirements of the Companies Act 2006. They are also responsible for safeguarding the assets of the Company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The above report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

On behalf of the Directors


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Mr P Trill
Director

Date: 27/01/24.

CURE CLCN4 (a company limited by guarantee)

Combined Statement of Financial Activities and Income Statement for the period ended 31 December 2023

			2023		2022
	Note	Restricted £	Unrestricted £	Total £	Total £
INCOME FROM					
Donations	3	-	78,479	78,479	23,492
Other income		-	-	-	-
Total Income		<u>-</u>	<u>78,479</u>	<u>78,479</u>	<u>23,492</u>
EXPENDITURE ON					
Charitable activities			-	-	-
Administration	4		118,510	115,115	45,352
Total expenditure			<u>118,510</u>	<u>115,115</u>	<u>45,352</u>
Net incoming/(outgoing) resources			<u>(40,031)</u>	<u>(36,636)</u>	<u>(21,860)</u>
Total funds brought forward			<u>43,702</u>	<u>43,702</u>	<u>65,562</u>
Total funds at 31 December 2023			<u>3,671</u>	<u>7,066</u>	<u>43,702</u>

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing activities.

CURE CLCN4 (a company limited by guarantee)

Balance sheet as at 31 December 2023

	Note	2023	2022
		£	£
Current Assets			
Cash at bank and in hand	5	23,886	56,135
Total assets		23,886	56,135
Creditors: Amounts falling due within one year	6	(20,215)	(12,433)
Net Current Assets		3,671	43,702
Total Assets Less Current Liabilities		3,671	43,702
Funds			
Unrestricted funds		3,671	43,702
		3,671	43,702

For the financial period ended 31 December 2023 the company was entitled to exemption from audit under section 477 of the Companies Act 2006. The members have not required the company to obtain an audit of these financial statements pursuant to section 476 of the Companies Act 2006.

The directors acknowledge their responsibilities for ensuring that the company keeps accounting records which comply with Section 368 of the Act and for preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of the financial period and of its surplus or deficit for the financial period in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to accounts, so far as applicable to the company.

These accounts have been prepared in accordance with the provisions applicable to small companies subject to the small companies' regime and in accordance with FRS102 SORP.

Approved on 27/01/24. and signed on behalf of all directors by:


Mr P Trill
Director

Company Number: 12447230

CURE CLCN4 (a company limited by guarantee)

Notes forming part of the accounts for the year ended 31 December 2023

1 BASIS OF PREPARATION

Cure CLCN4 is a company limited by guarantee incorporated in England and Wales.

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK (FRS 102) (effective 1 January 2015), the Financial Reporting Standard applicable in the UK (FRS 102), the Companies Act 2006 and the Charities Act 2011.

The Charity constitutes a public benefit entity as defined by FRS 102.

The accounts have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant notes to these accounts.

2 ACCOUNTING POLICIES

2.1 Incoming resources

All income is recognised once the charity has entitlement to the income, there is sufficient certainty of receipt and so it is probable that the income will be received, and the amount of income received can be measured reliably.

2.2 Offsetting

There has been no offsetting of assets and liabilities, or income and expenses, unless required or permitted by the FRS 102 SORP or FRS 102.

2.3 Grants and donations

Grants and donations are only included in the SoFA when the general income recognition criteria are met (5.10 to 5.12 FRS102 SORP).

2.4 Direct charitable resources expended

Direct charitable expenditure includes the direct costs in furtherance of the charity's objectives and are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably. Expenditure is accounted for under the accruals concept.

2.5 Administration resources expended

Administration costs represent the running costs of the charity and are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably. Expenditure is accounted for under the accruals concept.

CURE CLCN4 (a company limited by guarantee)

Notes forming part of the accounts for the period ended 31 December 2023 (continued)

3 Income from donations

	2023	2022
	£	£
Donations	78,479	23,492
	<u>78,479</u>	<u>23,492</u>

4 Expenditure

	2023	2022
	£	£
Expenditure on charitable activities	-	-
Staff Wages	8,105	37,282
Staff pension	180	2,153
Conferences	14,960	4,103
Subscriptions	485	108
Research costs	58,083	325
Bank and processing fees	446	445
Insurance	235	356
Computer expenses	158	320
Accountancy	1,208	128
Consultancy	34,650	-
Advertising	-	132
	<u>118,510</u>	<u>45,352</u>

5 Cash at bank and in hand

	2023	2022
	£	£
Cash at bank and on hand	23,886	56,135
	<u>56,135</u>	<u>56,135</u>

6 Creditors: amounts falling due within one year

	2023	2022
	£	£
Accruals	2,024	816
Other creditors	-	179
PAYE & Pension	145	-
Loan from director	18,046	11,438
	<u>20,215</u>	<u>12,433</u>

CURE CLCN4 (a company limited by guarantee)

Notes forming part of the accounts for the period ended 31 December 2023 (continued)

7 Funds of the Company

All funds held by the company are unrestricted and are to be used in the furtherance of the company's objectives as outlined in the directors' report on page 2.

8 Related party transactions and Trustees' Remuneration and expenses

Donations (Note 3) include a £50,000 contribution made by P Trill, a director of the company.

At 31 December 2023, £18,046 (2022 - £11,438) was owed to P Trill in relation to expense payments made on behalf of the company.

The trustees all give freely their time and expertise without any form of remuneration or other benefit in cash or kind. None of the trustees were paid expenses during the year.

Lewin Accounts Ltd/Chartered Accountants

Independent examiner's report to the Trustees of Cure CLCN4 Ltd

Registered Charity England and Wales, No. 1190344, Company number 12447230

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2023.

Responsibilities and basis of report

As the charity trustees of the Company (who are also the directors of the company for the purposes of company law), you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

Having satisfied myself that the accounts of the Company are not required to be audited for this year under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ("the 2011 Act"). In carrying out my examination, I have followed the Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act).

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention which gives me cause to believe that:

- accounting records were not kept in accordance with section 386 of the Companies Act 2006; or
- the accounts do not accord with such records; or
- the accounts do not comply with relevant accounting requirements under section 396 of the Companies Act 2006 other than any requirement that the accounts give a "true and fair" view which is not a matter considered as part of the independent examination; or
- the accounts have not been prepared in accordance with the Charities SORP (FRS 102)

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 a proper understanding of the accounts to be reached.



Colin Lewin, FCA
Mercury House
19-21 Chapel Street
Marlow
Bucks. SL7 3HN
29 January 2024