

CURE CLCN4 LTD

England & Wales · Charity number 1190344

Details

Status	Registered
Legal form	Charitable company
Company number	12447230
Registered	2020-07-10
Register	View on the Charity Commission register

Contact

Address	2 Duke Street London W1U 3EH
Phone	+442079350992
Email	peter.t@cureclcn4.org
Website	https://cureclcn4.org

Activities

Objects: THE OBJECTS OF THE CHARITY 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.

Activities: We are a registered charity aimed at providing support, raising awareness and funding medical research for effective treatments for CLCN4. CLCN4 is a rare genetic condition that causes intellectual disability and other problems such as epilepsy, behavioural disorders, movement disorders and microcephaly.

Classification

- **How:** Makes Grants To Organisations, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives
- **Who:** The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-12-31	£184,961	£197,019	-	-
2024-12-31	£88,637	£88,907	-	-
2023-12-31	£78,479	£118,510	-	-
2022-12-31	£23,492	£45,352	-	-
2021-12-31	£107,720	£33,098	-	-
2020-12-31	£0	£8,548	-	-

Trustees

Name	Role	Appointed
Peter James Alistair Trill	Chair	2020-02-06
Alexis Karim		2020-02-06
Dr Alan Wise		2020-02-06
Larry Louison		2020-02-06
Paul McGuinness		2022-06-07
Wang Sin Tan		2020-02-06

CURE CLCN4 LTD

England & Wales - Charity number 1190344

Accounts

REPORT & FINANCIAL STATEMENT

2025



Financial Statements for the
period ended 31 December 2025

Company Number: 12447230

Charity Reg. Number: 1190344

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ABOUT US

Cure CLCN4 is a UK-registered charity focused on providing **support**, raising **awareness** and, funding scientific **research** for effective treatments for *CLCN4*-related condition. Cure CLCN4 was founded by Peter Trill and Gina Tan (W Tan), the parents of Daphne, a little girl with *CLCN4*-related condition.



“

Cure CLCN4 was set up with the goal of advancing the much-needed basic science and translational research in this condition. It is built on the foundation of hope and commitment, that one day there would be a cure for Daphne and children like her.

”

About CLCN4-related condition

CLCN4-related neurodevelopmental condition (CLCN4-NDC) is a rare genetic condition that can affect brain development and learning. People with *CLCN4*-NDC may have intellectual disability, as well as epilepsy, behavioural challenges, movement difficulties, and other symptoms. So far, just over 150 families have been identified worldwide, but the true number of people affected is still unknown. Because the condition is so rare and still not widely recognised, many families face a long journey to get answers. There is also very limited information about how the condition develops and why it affects people so differently. Symptoms and severity can vary widely from one person to another. Since so little is currently known about CLCN4-NDC, there are no targeted treatments yet, and much more research is urgently needed.

Our mission

To improve the understanding and treatment of *CLCN4*-related condition through research, support for diagnosed individuals and their families, and awareness initiatives. We are committed to creating collaborations among scientists, healthcare professionals, and the patient community to develop effective treatments and improve the lives of those living with *CLCN4*-related condition.



Our vision

A world where a diagnosis of a *CLCN4*-related condition comes with hope and support, not uncertainty. We aim to transform the landscape of *CLCN4* research, ensuring that every diagnosed family has access to precise, comprehensive information, effective disease-specific therapies, and a supportive community.



OUR TRUSTEES



PETER TRILL

(CO-FOUNDER & TRUSTEE)

Peter is a co-founder of the UK registered Charity, Cure CLCN4. He is a father of three awesome children, the youngest of whom is affected by CLCN4. He is a company founder and board member working in the biotechnology sector. He is also a seed investor and mentor to founders of early-stage healthcare and technology companies.



DR. GINA TAN (W TAN)

(CO-FOUNDER & TRUSTEE)

Gina is a co-founder of Cure CLCN4, a medical clinician and mother to two girls, the younger being affected by CLCN4. She studied medicine at King's College London and trained in hospitals in London and Bath, subspecialising in Rheumatology. She undertook clinical research training at Queen Mary University London.



DR. ALAN WISE

(TRUSTEE)

Alan is a Trustee at Cure CLCN4. He is an experienced and successful biotech entrepreneur with in-depth knowledge of drug discovery. He is currently CEO of Duke Street Bio. Previous roles include CEO of the successful biotech, Iomet Pharma which was acquired by MSD in 2016 and senior drug discovery roles in large Pharma (GlaxoSmithKline).



LARRY LOUSION

(TRUSTEE)

Larry is a Trustee at Cure CLCN4 and a partner at TC Group (London). He is a fellow of the Association of Chartered Certified Accountants with over 20 years experience in general practice. Being very passionate about the goals of CureCLCN4, Larry is committed to using his skills and experience to build a strong financial infrastructure within the company.



PAUL MCGUINNESS

(TRUSTEE)

Paul is a technology consultant who has founded and been involved in various tech start-ups and is passionate about the power of technology to improve the way we interact, work and live. He aims to bring his experience with technology platforms to grow awareness about CLCN4 and make a long term positive impact for affected families.

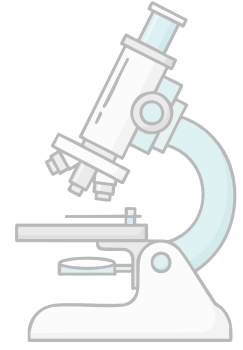


ALEXIS KARIM

(TRUSTEE)

Alexis is a Trustee at Cure CLCN4. He is also a Corporate Partner at Charles Russell Speechlys. He holds a strong interest in science and medicine and often seeks to combine this with his role as a lawyer.

OUR WORK



Scientific research

- Funded the generation of three **CLCN4-rat models**, which have been made available to the scientific community via the Infrafrontier repository. Characterisation work is ongoing.
- Established a biorepository of *CLCN4*-derived patient fibroblasts at Leiden University. Samples are being reprogrammed into **induced pluripotent stem cells (iPSCs)**. Two lines have been completed, and two are in progress, with plans to continue expanding the number of available lines.
- We collaborate with Simons Searchlight to support recruitment to the **CLCN4 patient registry**, which currently includes over 70 individuals.
- We have brought together a **community of scientists and clinicians** working on *CLCN4*-related condition and related fields, supporting the establishment of meaning collaborations and expanding the research network around this condition. We have achieved this via the organisation of our annual scientific conference, running since 2022.
- In 2024 we launched our **first grant program**, 150,000 GBP which has been used to fund three projects on *CLCN4*-related condition: i) characterisation of *CLCN4*-rat models; ii) functional analysis of newly identified *CLCN4*-variants of unknown significance and iii) electrophysiological examination of neuronal electrical activity in *CLCN4* rat models.
- Supported recruitment for a pilot study aimed at assessing the **speech & language** abilities of individuals with *CLCN4*-related condition (Garrett et al, 2025).

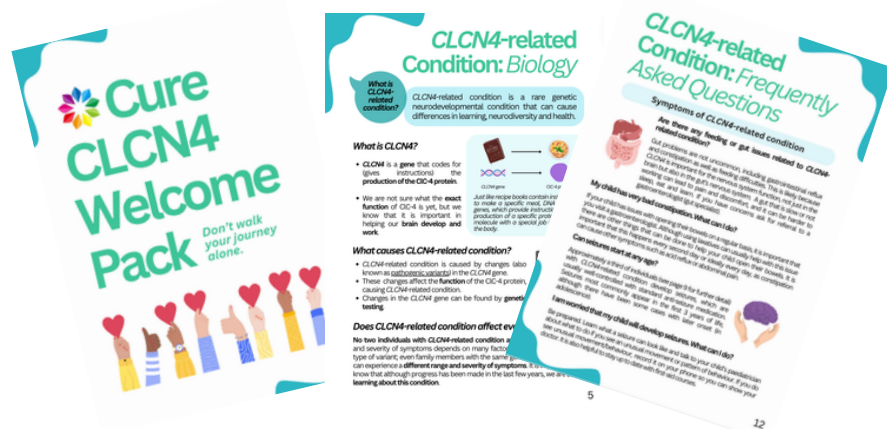


2025 Scientific Conference

Community support

Although the focus at Cure CLCN4 is to move the research forward, we also aim to support the CLCN4 community. Below are some of our initiatives:

- **Family Conferences:** We have held three online meetings for individuals with *CLCN4*-related condition and their families. During these conferences we invite speakers working on *CLCN4*-related condition to explain the current state of research in an accessible, family-friendly format. We also include Q&As, a panel of expert clinicians and scientists, and give families the opportunity to ask questions.
- **Informational resources:** Most information about *CLCN4*-related condition is available via research publications. Cure CLCN4 aims to make this information accessible to families of all over the world by providing family-friendly summaries of recent publications (<https://cureclcn4.org/palmer-et-al-2022-a-summary-for-families/>). We have also created the Cure CLCN4 Welcome Pack which contains expert-checked, up-to-date information on *CLCN4*-condition including biology, genetics, clinical care, FAQs, etc (https://cureclcn4.org/resources_families/)



- **Community connection & support:** We actively connect families around the world so they can share experiences, ask questions, and learn from others who understand the condition. We do this through a private Facebook group, via online community-wide family meetings, and by connecting families from the same country/area. For many, this is the first time they meet someone facing similar challenges.



Legal and administrative information

Governed by

Memorandum and Articles of Association dated 6 February 2020.

Trustees

P Trill
A Karim
Gina Tan (W Tan)
A Wise
L Louison
P McGuinness

Registered Office

2 Duke Street
London
W1U 3EH

Registered charity number

1190344

Company Number

12447230

Accountants

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

Independent Examiner

Sterling Grove Accountants
Chartered Certified Accountants
2 Regatta Place
Fawley House
Marlow Road
Bourne End
Buckinghamshire
SL8 5TD

Trustees' Report

The trustees, who are Directors for the purposes of company law, present the annual report together with the financial statements and auditors' report of the charitable company for the year ended 31 December 2025.

TRUSTEES

The trustees serving during the year are as follows:

P Trill
A Karim
Gina Tan (W Tan)
A Wise
L Louison
P McGuinness

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 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 organization 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:

Trustees' report continued

- i) Providing relief and assistance to people suffering from pathogenic variants of clcn4;
- 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;

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.

PUBLIC BENEFIT

Cure CLCN4 provides public benefit by advancing knowledge, awareness and understanding of CLCN4-related neurodevelopmental condition, a rare genetic condition affecting individuals and families worldwide. The charity supports research, promotes collaboration between clinicians, scientists and families, and provides accessible information and resources to help families better understand the condition and engage with research opportunities. Through its activities, Cure CLCN4 aims to improve diagnosis, care, support and, in the longer term, the development of disease-specific therapeutic approaches for people affected by CLCN4-related condition.

ACHIEVEMENTS AND PERFORMANCE

Research and scientific progress

During 2025, Cure CLCN4 continued to support research into CLCN4-related condition through its pilot grant program, with funded projects progressing and end-of-grant reporting undertaken where applicable. The charity also continued its efforts to establish CLCN4 patient-derived cell lines for use in research, in collaboration with Leiden University, an important resource to support future studies into the condition.

The charity held its 2025 Scientific Conference in May, bringing together researchers, clinicians and other stakeholders to share progress, strengthen collaboration and encourage further interest in CLCN4 research. The event also supported engagement from early-career researchers through poster and lightning talk sessions.

Cure CLCN4 also supported work that contributed to the publication of a speech and language study in individuals with CLCN4-related condition, helping to expand knowledge of the communication profile and needs of individuals affected by CLCN4-related condition. The patient registry continued to grow during the year, supporting better understanding of CLCN4-related condition.

Families & community

Cure CLCN4 continued to grow and strengthen its international community of families during 2025. The charity maintained direct engagement with families through calls, events and online communications, helping families feel connected, informed and supported.

Trustees' report continued

The 2025 Family Conference was the charity's largest family meeting to date and provided an opportunity for families to hear updates, ask questions and connect with others with shared experience. Translation support helped make the event more accessible to non-English-speaking families. The charity also expanded accessible resources for families, including the Cure CLCN4 Welcome Pack, which was translated into multiple languages and made available online. Cure CLCN4 also helped identify families with variants of uncertain significance and supported appropriate referral to clinical and research experts, contributing to wider efforts to improve understanding of CLCN4 variants.

Awareness, communications and community building

The charity continued to raise awareness of CLCN4-related condition through its website, social media and communications activity. During the year, Cure CLCN4 shared updates about research, events, family resources and scientific developments. Communications activity helped increase visibility of the condition, support family engagement and encourage participation in the registry and other research-related activities.

Overall impact

Overall, Cure CLCN4's work in 2025 made a tangible difference by strengthening the research infrastructure for CLCN4-related condition, increasing patient registry participation, improving access to family information and support, and building collaboration across families, clinicians and researchers. The charity's activities helped ensure that a very rare condition remains visible, studied and better understood, while laying foundations for improved care, future therapeutic research and greater support for affected families worldwide.

FINANCIAL REVIEW

Total Income for the year was £184,961 (2024: £88,637) split between unrestricted income of £166,302 and restricted income of £18,659.

The charities accounts show a deficit of £8,657 (2024: £3,401 surplus.)

This is our sixth year of operations, during which we have continued to strengthen both our research programme and our support for the CLCN4 community. Over the past year, we have made important progress in research, including the generation of the first two induced pluripotent stem cell (iPSC) lines and the development of a strategic research plan to help guide future priorities. In addition, two of the three Cure CLCN4-funded research projects have now been completed. Alongside this, our family community has continued to grow, and we remain committed to providing connection, information and practical resources to those affected by CLCN4-related condition. We have also continued to expand our fundraising efforts to support both current activities and future research. This year, we were also pleased to celebrate our fourth scientific conference and our third family meeting, both of which continue to strengthen collaboration, shared learning and community engagement.

POLICY ON RESERVES

The Trustees have adopted a Reserves Policy which sets out the charity's approach to reserves, including the definition of free reserves, why reserves are held, and how the target level is calculated, monitored and replenished. The policy applies to unrestricted funds only and defines free reserves as unrestricted funds available for general use after deducting designated funds and unrestricted tangible fixed assets. The Trustees have determined that Cure CLCN4 should maintain free reserves equivalent to 5–6 months of planned operating expenditure. This level is considered sufficient to manage temporary income gaps, meet unexpected costs, provide orderly wind-down funding if required, and allow the charity to respond to time-sensitive strategic opportunities. At 31 December 2025, the charity held free reserves of £(8,657) (2024: £3,401). This is below the target range set by the Trustees. The Trustees continue to monitor reserves regularly and will agree actions to restore reserves to the target range, including cost control, targeted fundraising and careful management of future commitments.

PLANS FOR FUTURE PERIODS

In future periods, Cure CLCN4 plans to finalise the current CLCN4 Pilot Grant programme, including completion of final reporting and consideration of how the data and findings generated can inform future research priorities. The charity will continue to support initiatives aimed at improving understanding of the basic biology of CLCN4 and the mechanisms underlying CLCN4-related condition.

Cure CLCN4 will continue to grow the patient registry and support families to complete the registration process. The charity also intends to expand the range of CLCN4 variants for which patient-derived samples are available, helping to build research resources that can support future functional studies.

The charity will continue to grow both the research and family communities through scientific meetings, family events, direct family engagement and international collaboration. It will also continue to create and translate accessible resources for families, ensuring that information is available to international families and those who do not speak English as a first language.

To support these plans, Cure CLCN4 will seek to strengthen fundraising activity, increase the number of grant and trust applications submitted, and grow grant and corporate funding. The charity will also continue to develop its communications and partnerships to raise awareness of CLCN4-related condition and broaden support for its work.

Trustees' report continued

STATEMENT OF TRUSTEES' RESPONSIBILITIES

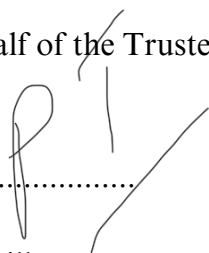
The Trustees' are required under company law to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law Trustees' 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 Trustees' are required to:

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

The Trustees' 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 Trustees

A handwritten signature in black ink, appearing to be 'P Trill', is written over a horizontal dotted line.

Mr P Trill
Director

Date: 03.06.2026

CURE CLCN4 Limited

Independent Examiner's Report to the trustees of Cure CLCN4 Limited ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2025.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors 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 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 matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of Cure CLCN4 Limited as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (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.



Mr G P Amasanti FCCA
Chartered Certified Accountants
Sterling Grove Accountants
2 Regatta Place
Fawley House
Marlow Road
Bourne End
Buckinghamshire
SL8 5TD
Date: 4/6/20

Combined Statement of Financial Activities and Income Statement for the period ended 31 December 2025

	Note	Restricted £	2025 Unrestricted £	Total £	2024 Total £
INCOME FROM					
Donations	3	18,659	166,302	184,961	88,637
Other income		-	-	-	-
Total Income		<u>18,659</u>	<u>166,302</u>	<u>184,961</u>	<u>88,637</u>
EXPENDITURE ON					
Charitable activities	4	-	114,751	114,751	24,681
Administration	4	18,659	63,609	82,268	64,226
Total expenditure		<u>18,659</u>	<u>178,360</u>	<u>197,019</u>	<u>88,907</u>
Net incoming/(outgoing) resources		-	(12,058)	(12,058)	(270)
Total funds brought forward		-	3,401	3,401	3,671
Total funds at 31 December 2025		<u>-</u>	<u>(8,657)</u>	<u>(8,657)</u>	<u>3,401</u>

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

Balance sheet as at 31 December 2025

	Note	2025	2024
		£	£
Current Assets			
Cash at bank and in hand	8	10,460	29,619
Debtors	9	821	-
Total assets		11,281	29,619
Creditors: Amounts falling due within one year	10	(19,938)	(26,218)
Net Current liabilities		(8,657)	3,401
Total Assets Less Current Liabilities		<u>(8,657)</u>	<u>3,401</u>
Funds			
Unrestricted funds		(8,657)	3,401
		<u>(8,657)</u>	<u>3,401</u>

For the financial period ended 31 December 2025 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 trustees 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

and signed on behalf of all directors by:

Mr P Trill
Director

Company Number: 12447230

Notes forming part of the accounts for the year ended 31 December 2025

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.

The registered office address is 2 Duke Street, London, W1U 3EH.

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).

Unconditional grants are recognised as a liability and an expense as soon as the grantee is notified of the award.

Conditional grants are recognized as an expense only when the grantee fulfils the specific performance-related conditions.

Notes forming part of the accounts for the year ended 31 December 2025

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.

2.6 Fund structure

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for a specific purpose, the use of which is restricted to that area or purpose. Restricted income received during the year to 31 December 2025 were for the funding and sponsorship of the annual conference.

3 Income from donations

	2025	2024
	£	£
Donations	158,363	80,711
Grants	20,348	0
Sponsorship	6,250	7925
	<u>184,961</u>	<u>88,636</u>

A £7,000 grant from Highway One Trust was received in December 2024 but relates to activities taking place in 2025. It has therefore been treated as deferred income at 31 December 2024 and recognised in income in 2025.

Donations above include restricted funds of £18,659 (2024 – Nil) for the funding of the annual conference. All restricted funds were used during the financial year.

Notes forming part of the accounts for the year ended 31 December 2025

4 Expenditure

	2025	2024
	£	£
Expenditure on charitable activities	114,751	24,681
Administration		
Staff Wages	5,200	4,983
Conferences	22,489	15,258
Subscriptions	2,390	368
Bank and processing fees	626	439
Travel	69	75
Insurance	301	233
Accountancy	1,380	210
Consultancy	49,536	42,660
Sundry expenses	277	-
	82,268	64,226

5 Independent Examiners' Remuneration

	2025	2024
	£	£
Examination of Financial statements	720	660
	720	660

6 Average number of employees

	2025	2024
	£	£
Average number of employees	1	1
	1	1

No employee received emoluments of more than £60,000 during the year.

7 Taxation

The Charity is a registered charity and is therefore exempt from taxation

Notes forming part of the accounts for the year ended 31 December 2025

8 Cash at bank and in hand

	2025	2024
	£	£
Cash at bank and on hand	10,460	29,619
	<u>10,460</u>	<u>29,619</u>

9 Debtors

	2025	2024
	£	£
Other debtors	821	-
	<u>821</u>	<u>-</u>

10 Creditors: amounts falling due within one year

	2025	2024
	£	£
Accruals and deferred income	1,837	8,117
PAYE	55	55
Loan from director	18,046	18,046
	<u>19,938</u>	<u>26,218</u>

11 Grant-making**Analysis of grants**

	2025	2024
	£	£
	Grants to institutions	Grants to institutions
Istituto di Biofisica, Consiglio Nazionale delle Ricerche	15,836	3,479
Le Centre Européen de Recherche en Biologie et en Médecine	65,401	9,599
Forschungszentrum Jülich GmbH	14,869	10,131
	<u>96,106</u>	<u>23,209</u>

In 2025, Cure CLCN4 supported three research projects through the Cure CLCN4 Pilot Grant scheme. These grants were awarded to research groups working to improve understanding of *CLCN4*-related neurodevelopmental condition and to support early-stage research that may inform future diagnosis, treatment and care.

The grants supported:

- Raul E. Guzman, Research Center Juelich: research into the electrical activity of hippocampal neurons in *CLCN4* rat models. This project examined how changes in CLCN4 affect neuronal excitability and identified altered firing patterns that may help explain disease mechanisms.
- Yann Herault and Tania Sorg, PHENOMIN–ICS, CERBM GIE: characterisation of *CLCN4* rat models carrying loss-of-function and A549V mutations. The project assessed behavioural, neurological, motor, growth and gastrointestinal features, helping to establish whether these models reflect symptoms seen in people with CLCN4-related conditions.
- Michael Pusch, Istituto di Biofisica, CNR: functional analysis of *CLCN4* variants. This project is testing how different variants affect ClC-4 function and its interaction with ClC-3, helping to classify variants and improve understanding of the molecular mechanisms underlying CLCN4-related conditions.

Together, these projects advanced knowledge of CLCN4 biology, disease models and variant function, and provided foundations for future research into potential therapeutic approaches.

No grants were made to individuals.

12 Funds of the Company

All funds held by the company at 31 December 2025 are unrestricted and are to be used in the furtherance of the company's objectives as outlined in the Trustees' report on p. 8-12.

13 Analysis of Funds

Unrestricted Funds

	Balance at 1 January 2025 £	Incoming resources £	Resources expended £	Balance at 31 December 2025 £
General Core	3,401	166,302	(178,360)	(8,657)
Restricted funds				
2025 Annual conference	-	18,659	(18,659)	-
Total funds	<u>3,401</u>	<u>184,961</u>	<u>(197,019)</u>	<u>(8,657)</u>

Notes forming part of the accounts for the year ended 31 December 2025

Unrestricted Funds

	Balance at 1 January 2024	Incoming resources	Resources expended	Balance at 31 December 2024
	£	£	£	£
General Core	3,671	88,637	(88,907)	3,401
Total funds	<u>3,671</u>	<u>184,961</u>	<u>(196,299)</u>	<u>3,401</u>

14 Analysis of net assets between funds

	Unrestricted funds general	Restricted funds	Total funds at 31 December 2025
	£	£	£
Current assets	11,281	-	11,281
Current liabilities	<u>(19,638)</u>	<u>-</u>	<u>- 19,938</u>
Total net liabilities	<u>(8,657)</u>	<u>-</u>	<u>(8,657)</u>

	Unrestricted funds general	Restricted funds	Total funds at 31 December 2024
	£	£	£
Current assets	29,619	-	29,619
Current liabilities	<u>(26,218)</u>	<u>-</u>	<u>(26,218)</u>
Total net liabilities	<u>3,401</u>	<u>-</u>	<u>(3,401)</u>

15 Related party transactions and Trustees' Remuneration and expenses

Donations (Note 3) include a £141,681 contribution made by P Trill, a director of the company.

At 31 December 2025, £18,046 (2024 - £18,046) 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

Get in touch



info@cureclcn4.org



www.cureclcn4.org



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 1st January 2025 **Period start date** **To** 31st December 2025
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 several CLCN4 patient-derived cell lines), and continued supporting 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 fourth 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. We also organised an online Family Meeting for families living with CLCN4-related condition. The meeting included short talks from invited speakers as well as a panel Q&A during which families had the chance to ask questions.

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	The charity's financial position at the end of 2025 is healthy with a balance of 8,657 GBP. This is the fifth 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 2025 fell below the level desired by the trustees this will be replenished in early 2026 by a cash donation from Peter Trill, a charity trustee.
Amount of reserves held	Para 1.22	8,657 GBP
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			
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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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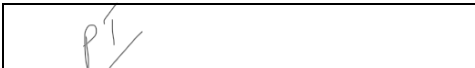
Other optional information

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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	09/06/2026	

CURE CLCN4 LTD

England & Wales - Charity number 1190344

Accounts



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 1st January 2024 **Period start date** **To** 31st December 2024
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	During 2024 Cure CLCN4 LTD awarded the first research grants, supporting three projects focused on better understanding the biology of CLCN4-related condition. We have also continued to support efforts aimed at developing important research tools, such as a CIC-4 antibody for use in basic research. We successfully organised the 3rd Annual Cure CLCN4 Scientific Conference, held in London. We have continued to expand and strengthen our research network. We also continue to support families and individuals living with CLCN4-related condition. In 2024 we organised the second online family meeting, which brought together over 50 families. Families had the chance to ask question to a panel of clinical and research experts. We have also continued to offer support in the form of accessible informational resources, opportunities to participate in research and to connect with the rest of the community.

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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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 2024 is healthy with a balance of 3,401GBP. This is the fourth 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 five to 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 2024 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	3,401GBP
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		

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Description of charity's trusts:		
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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:

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Relationship with any related parties	Para 1.51	
Other		

Reference and Administrative details

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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			
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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)

--

Exemptions from disclosure

Reason for non-disclosure of key personnel details

--

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	28/09/2025	

2024

Report & Financial statement



(a company limited by guarantee)

Financial Statements
for the period ended
31 December 2024



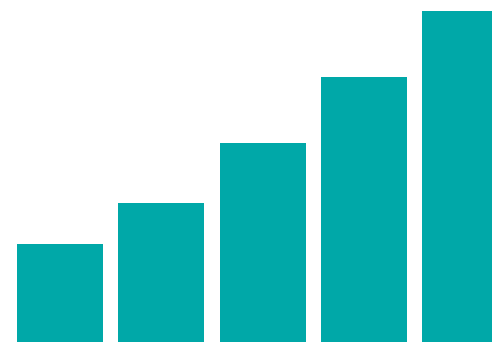
Company Number:
12447230

Charity registration number:
1190344



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About Us

We are a registered charity aimed at providing **support**, raising **awareness** and funding medical and scientific **research** for effective treatments for *CLCN4*-related condition.

CLCN4 is a rare genetic condition that causes intellectual disability and other problems such as epilepsy, behavioural disorders, movement disorders and microcephaly.



Meet Our Founders

Cure CLCN4 was co-founded by Peter Trill and Gina Tan. Their journey began with the birth of their youngest child, Daphne, who was diagnosed with *CLCN4*-related condition. Faced with limited knowledge and a lack of treatment options, they began connecting with other affected families and experts in the field. Recognising the urgent need for greater awareness and scientific progress, they established Cure CLCN4 to help drive research and support families impacted by the condition. Their vision continues to guide the charity's mission to promote basic and translational research aimed at understanding *CLCN4* and identifying effective treatments.



Meet Our Trustees



PETER TRILL (CO-FOUNDER & TRUSTEE)

Peter is a co-founder of the UK registered Charity, Cure CLCN4. He is a father of three awesome children, the youngest of whom is affected by CLCN4. He is a company founder and board member working in the biotechnology sector. He is also a seed investor and mentor to founders of early-stage healthcare and technology companies



GINA TRILL (CO-FOUNDER & TRUSTEE)

Gina is a co-founder of Cure CLCN4, a medical clinician and mother to two girls, the younger being affected by CLCN4. She studied medicine at King's College London and trained in hospitals in London and Bath, subspecialising in Rheumatology. She undertook clinical research training at Queen Mary University London.



ALAN WISE (TRUSTEE)

Alan is a Trustee at Cure CLCN4. He is an experienced and successful biotech entrepreneur with in-depth knowledge of drug discovery. He is currently CEO of Duke Street Bio. Previous roles include CEO of the successful biotech, Iomet Pharma which was acquired by MSD in 2016 and senior drug discovery roles in large Pharma (GlaxoSmithKline).



ALEXIS KARIM (TRUSTEE)

Alexis is a Trustee at Cure CLCN4. He is also a Corporate Partner at Charles Russell Speechlys. He holds a strong interest in science and medicine and often seeks to combine this with his role as a lawyer.



LARRY LOUSION (TRUSTEE)

Larry is a Trustee at Cure CLCN4 and a partner at TC Group, based in the London office. He is a fellow of the Association of Chartered Certified Accountants with over 20 years experience in general practice. Being very passionate about the goals of CureCLCN4, Larry is committed to using his skills and experience to build a strong financial infrastructure within the company.



PAUL MCGUINNESS (TRUSTEE)

Paul began his career as a technology consultant at Apple at the launch of the original iPhone and App Store. He has founded and been involved in various tech start-ups and is passionate about the power of technology to improve the way we interact, work and live. Paul aims to bring his experience with technology platforms to grow awareness about CLCN4 and make a long term positive impact for families who have a loved one with the condition.

Vision & Mission

Mission

Our mission is to enhance the understanding and treatment of *CLCN4*-related condition through research, in addition to supporting affected individuals and their families, and driving awareness initiatives. We are committed to fostering collaboration among scientists, healthcare professionals, and communities to discover effective treatments and improve the lives of those impacted by *CLCN4*-related condition.



Vision



Our vision is a world where a diagnosis of a *CLCN4*-related condition comes with hope and support, not uncertainty. We aim to transform the landscape of *CLCN4* research, ensuring that every affected family has access to precise, comprehensive information, effective disease-specific therapies, and a supportive community. By connecting families with each other and with leading experts, we aim to foster a strong network of advocacy and aid, empowering individuals and their loved ones to face this challenge with knowledge and collective strength.

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

P 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

Director's report

The Directors' submit the organisations report for the period ended 31 December 2024.

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 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 organization 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*;
- 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*;

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 our fifth year of operations, during which we have continued to facilitate the development of research tools, including the generation of patient-derived cell lines, as well as an antibody for use in basic research. Additionally, we have given out our first research grants; we are currently funding three research projects focused on better understanding the biology of *CLCN4*-related condition. We also celebrated our third annual scientific conference, which has continued to grow in size and engagement. Our community of families has also grown and we continue to provide them with connection, information and resources, such as the recently launched Cure CLCN4 Welcome Pack, which contains up-to-date and accessible information on *CLCN4*-related condition.

Director's report continued

STATEMENT OF DIRECTORS' RESPONSIBILITIES

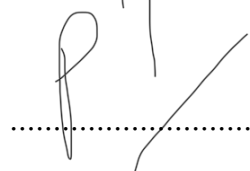
The Directors' are required under company law to prepare financial statements for each financial year. Under that law the directors have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable 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


.....

Mr P Trill
Director

Date: 31/07/2025

Combined Statement of Financial Activities and Income Statement for the period ended 31 December 2024.

	Note	Restricted £	2024 Unrestricted £	Total £	2023 Total £
INCOME FROM					
Donations	3	-	88,637	88,637	78,479
Other income		-	-	-	-
Total Income		-	88,637	88,637	78,479
EXPENDITURE ON					
Charitable activities			-	-	-
Administration	4		88,907	88,907	118,510
Total expenditure			88,907	88,907	118,510
Net incoming/(outgoing) resources			(270)	(270)	(40,031)
Total funds brought forward			3,671	3,671	43,702
Total funds at 31 December 2024			3,401	3,401	3,671

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

Balance sheet as at 31 December 2024.

	Note	2024	2023
		£	£
Current Assets			
Cash at bank and in hand	5	<u>29,619</u>	<u>23,886</u>
Total assets		29,619	23,886
Creditors: Amounts falling due within one year	6	<u>(26,218)</u>	<u>(20,215)</u>
Net Current Assets		3,401	3,671
Total Assets Less Current Liabilities		<u>3,401</u>	<u>3,671</u>
Funds			
Unrestricted funds		3,401	3,671
		<u>3,401</u>	<u>3,671</u>

For the financial period ended 31 December 2024 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 _____ and signed on behalf of all directors by:

Mr P Trill
Director



Company Number: 12447230

31/07/2025

Notes forming part of the accounts for the year ended 31 December 2024

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 2024 (continued)

3 Income from donations

	2024	2023
	£	£
Donations	88,636	78,479
	<u>88,636</u>	<u>78,479</u>

4 Expenditure

	2024	2023
	£	£
Expenditure on charitable activities	24,681	58,083
Staff Wages	4,983	8,105
Staff pension	-	180
Conferences	15,258	14,960
Subscriptions	368	485
Bank and processing fees	439	446
Travel	75	-
Insurance	233	235
Computer expenses	-	158
Accountancy	210	1,208
Consultancy	42,660	34,650
	<u>88,907</u>	<u>118,510</u>

5 Cash at bank and in hand

	2024	2023
	£	£
Cash at bank and on hand	21,619	23,886
	<u>21,619</u>	<u>23,886</u>

6 Creditors: amounts falling due within one year

	2024	2023
	£	£
Accruals and deferred income	8,117	2,024
Other creditors	-	-
PAYE & Pension	55	145
Loan from director	18,046	18,046
	<u>26,218</u>	<u>20,215</u>

CURE CLCN4 (a company limited by guarantee)

Notes forming part of the accounts for the period ended 31 December 2024 (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 pages 8 and 9.

8. Related party transactions and Trustees' Remuneration and expenses

Donations (Note 3) include a £50,347 contribution made by P Trill, a director of the company.

At 31 December 2024, £18,046 (2023 - £18,046) 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.

Our Activities

Scientific Research

Scientific research remains the central priority of Cure CLCN4. Our efforts are guided by the belief that meaningful progress for individuals affected by *CLCN4*-related condition depends on advancing our understanding of the underlying biology and developing effective treatments. Throughout 2024, we remained committed to supporting high-quality research and fostering collaboration across the scientific community.



• Cure CLCN4 Pilot Grant

We launched our first competitive funding initiative, the Cure CLCN4 Pilot Grant Programme, £150,000 aimed at supporting research projects with the potential to improve understanding and identify therapeutic strategies for *CLCN4*. As part of this grant we are funding the following projects:

“Deciphering the consequences of *CLCN4* loss-of-function & gain-of-function in rats to better understand *CLCN4*-related neurodevelopmental condition” - Dr. Yann Herault & Dr. Tania Sorg (IGBMC, France).

“Understanding the functional consequences of novel *CLCN4* variants using multifunctional analyses – from biophysics to subcellular trafficking” - Dr. Michael Pusch (Istituto di Biofisica, Italy).

“Electrophysiological examination of neuronal electrical activity in rat *Clcn4* KO and *Clcn4* A549V hippocampal cells” - Dr. Raul Guzman (FZ Julich, Germany).

• Development of research tools

In 2024, we continued to invest in the development of key research tools to support the global scientific community studying CLCN4-related conditions.

Generation of a ClC-4 antibody



Cure CLCN4 is collaborating with Dr. Raul Guzman (FZ Juelich), Dr. Stefanie Bungert (FZ Juelich), Dr. Heinrich Flaswinkel (Ludwig Maximilian University of Munich), and Dr. Vera Kalscheuer (Max Planck Institute) to develop a ClC-4 antibody for use in basic research.

Induced pluripotent stem cells (iPSCs)



CLCN4 patient-derived induced pluripotent stem cells are being generated by the Simons Foundation, using samples from patients in the Simons Searchlight patient registry. In addition, Cure CLCN4 is also collaborating with Dr. Marlen Lauffer (Dutch Centre for RNA Therapeutics) to establish a biobank of CLCN4-patient derived iPSCs, which will also be made available to the scientific community.

• Annual Scientific Conference



We hosted our third Cure CLCN4 Scientific Conference, bringing together researchers, clinicians, and families to foster collaboration and accelerate progress. The conference was held on 7th & 8th June 2024, in Central London (UK) and the program included 22 speakers and the event was attended by 75 participants, in person and online. The event also featured a poster session, which provided an opportunity for PhD students and early career researchers to participate.

Family support

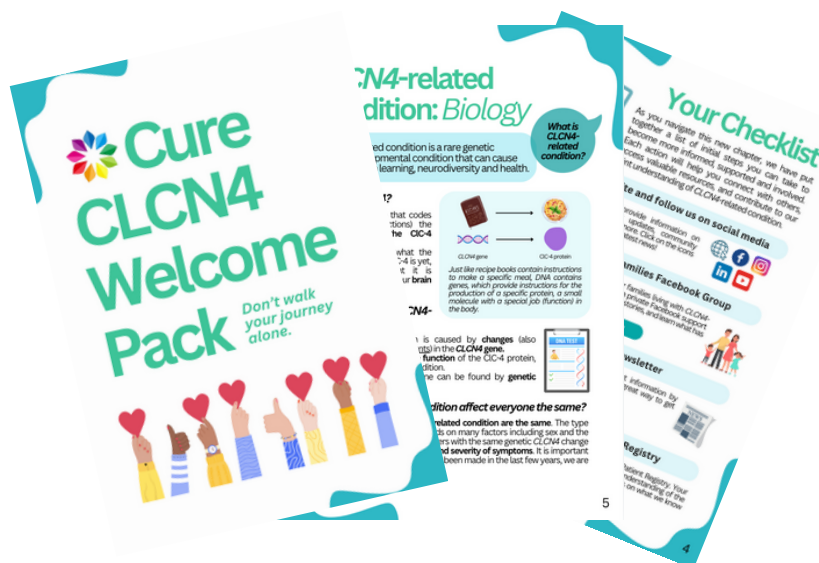


Family-focused events

On 6th June we celebrated our second online Family Meeting, attended by over 40 families from over 9 countries. The meeting featured an Expert Panel Q&A, during which families had the chance to ask questions to a group of clinical specialists, including a clinical geneticist, a neurologist, psychiatrist, and gastroenterologist, among others.

Resources

We released the Cure CLCN4 Welcome Pack, a comprehensive booklet filled with essential resources for families navigating life with *CLCN4*-related condition. It contains up-to-date information on the biology, diagnosis, and symptoms of *CLCN4* as well as frequently asked questions, resources, and ways to get involved!



Fundraising

Luca and Marco Run the 2024 Ibiza Marathon!



£8,512

raised of £4,000 target
by 121 supporters



After a previous fundraiser in 2023, where they raised over £15,000, Luca and Marco took on an even tougher challenge! Inspired by Luca's youngest sister, Daphne, who lives with a *CLCN4*-related condition, they decided to tackle the Ibiza 2024 Marathon. Despite the grueling training, they pushed through for this brilliant cause. Every donation went directly towards research to help advance our understanding and treatment of *CLCN4*. Thanks to their hard work and the incredible support from the community, they managed to make a big impact for Cure *CLCN4*!

Caroline's Colour Run for Cure *CLCN4*!

In 2024, Caroline and her brother took part in the vibrant Colour Run held in France, channeling every colourful step into meaningful support for Cure *CLCN4*. Through their energy and enthusiasm, they rallied friends and family to sponsor their run, collectively raising vital funds for research and awareness.





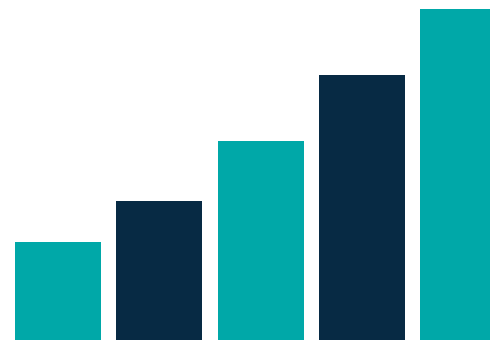
Contact Us



info@cureclcn4.org



www.cureclcn4.org



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 2024.

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
27 June 2025

CURE CLCN4 LTD

England & Wales - Charity number 1190344

Accounts



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		
-------	--	--

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)

--

Exemptions from disclosure

Reason for non-disclosure of key personnel details

--

Other optional information

--

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

Contents

Page

1	Legal and administrative information
2 -3	Directors' report
4	Statement of financial activities for the period ended 31 December 2023
5	Balance sheet as at 31 December 2023
6-8	Notes to the accounts

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


.....

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

CURE CLCN4 LTD

England & Wales - Charity number 1190344

Accounts



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 1st January 2021 Period start date To 31st December 2021
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 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	Cure CLCN4 LTD has successfully initiated projects for the generation/validation of important tools for the furthering of scientific research into CLCN4 condition (including an animal model as well as the first official registry for CLCN4 patients) We have worked on supporting affected families via the provision of accessible and up-to-date information on CLCN4 condition on our website as well as via the organisation of the first Cure CLCN4 Family Meeting. Hiring of a full-time research manager to ensure the continuity and progress of our activities towards the objectives of the charity.

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 2021 is healthy with a balance of GBP 65.5k. This is the first 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 and leaves us with enough reserves to carry out more and larger projects on the following year.
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 to project and operational need and ensure that support and governance costs are covered. The trustees consider that a level of 6 months is sufficient.
Amount of reserves held	Para 1.22	£65,562
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		June 2022 - present	
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

Corporate trustees' names or 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	
Date	26/10/2022	

CURE CLCN4
(a company limited by guarantee)

Financial Statements
for the period ended
31 December 2021

Company Number: 12447230

CURE CLCN4 (a company limited by guarantee)

Statement of accounts for the period ended 31 December 2021

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5	Balance sheet as at 31 December 2021
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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 (Appointed 7 June 2022)

Registered Office

2 Duke Street
London
W1U 3EH

Accountants

TC Group
Level One
Devonshire House
One Mayfair Place
London
W1J 8AJ

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 2021.

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 second year of operations, and the focus has been on continuing to build out and consolidate the infrastructure of the charity. Further, in line with the charity objectives we have organised events to support families and connect with the research community as well as worked on developing essential research tools such as an animal model and patient registry.

CURE CLCN4 (a company limited by guarantee)

Directors' Report (continued)

STATEMENT OF DIRECTORS' RESPONSIBILITIES

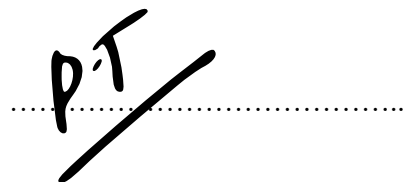
The Directors' are required under company law to prepare financial statements for each financial year. Under that law the directors have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable 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

A handwritten signature in black ink, appearing to be 'P. Trill', written over a horizontal dotted line.

Mr P Trill
Director

Date: 25/10/22

CURE CLCN4 (a company limited by guarantee)

Combined Statement of Financial Activities and Income Statement for the period ended 31 December 2021

	Note	Restricted £	2021 Unrestricted £	Total £	2020 Total £
INCOME FROM					
Donations	3		107,720	-	-
Other income			-	-	-
Total Income			<u>107,720</u>	<u>-</u>	<u>-</u>
EXPENDITURE ON					
Charitable activities			-	-	-
Administration	4		33,610		8,548
Total expenditure			<u>33,098</u>	<u></u>	<u>8,548</u>
Net incoming/(outgoing) resources			<u>74,110</u>	<u></u>	<u>(8,548)</u>
Total funds brought forward			<u>(8,548)</u>	<u></u>	<u>-</u>
Total funds at 31 December 2021			<u>65,652</u>	<u></u>	<u>(8,548)</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 2021

	Note	2021	2020
		£	£
Current Assets			
Cash at bank and in hand	5	77,628	2,890
Debtors	6	2,120	
Total assets		79,748	
Creditors: Amounts falling due within one year	7	(14,186)	(11,438)
Net Current Assets		65,562	(8,548)
Total Assets Less Current Liabilities		<u>65,562</u>	<u>(8,548)</u>
Funds			
Unrestricted funds		65,562	(8,548)
		<u>65,562</u>	<u>(8,548)</u>

For the financial period ended 31 December 2020 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 25/10/22 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 2021

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 2021 (continued)

3 Income from donations

	2021	2020
	£	£
Individual donations	119,158	-
	<u>119,158</u>	<u>-</u>

4 Expenditure

	2021	2020
	£	£
Expenditure on charitable activities	-	-
Staff Wages	18,793	-
Staff pension	1,139	-
Conferences	35	-
Research costs	5,055	-
Processing fees	528	-
Computer expenses	287	-
Accountancy	1,816	-
Consultancy	6,248	-
Advertising	(291)	1,450
Legal & Professional	-	7,098
	<u>33,610</u>	<u>8,548</u>

5 Cash at bank and in hand

	2021	2020
	£	£
Cash at bank and on hand	77,628	2,890
	<u>77,628</u>	<u>2,890</u>

6 Debtors

	2021	2020
	£	£
Amounts due from social platforms	2,120	-
	<u>2,120</u>	<u>-</u>

CURE CLCN4 (a company limited by guarantee)

Notes forming part of the accounts for the period ended 31 December 2021 (continued)

7 Creditors: amounts falling due within one year

	2021	2020
	£	£
Accruals	1,816	-
PAYE & Pension	932	-
Loan from director	11,438	11,438
	<u>14,186</u>	<u>11,438</u>

8 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.

9 Related party transactions and Trustees' Remuneration and expenses

During the year P Trill donated £87,500 to the company. P Trill is a director and trustee of Cure CLCN4.

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 2021.

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
25 October 2022