

REPORT & FINANCIAL STATEMENT

2025



Financial Statements for the
period ended 31 December 2025

Company Number: 12447230

Charity Reg. Number: 1190344

TABLE OF CONTENTS

About Us.....	p.3
Our Trustees.....	p.4
Our Work.....	p.5-6
Legal & Administrative Information.....	p.7
Trustees' Report.....	p.8-12
Independent Examiner's Report.....	p.13
Statement of financial activities for the period ended 31 December 2025.....	p.14
Balance sheet as at 31 December 2025.....	p.15
Notes to the accounts.....	p.16-21
Get in touch.....	p.22

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.

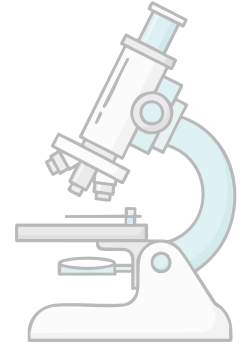


ALEXIS KARIM

(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).

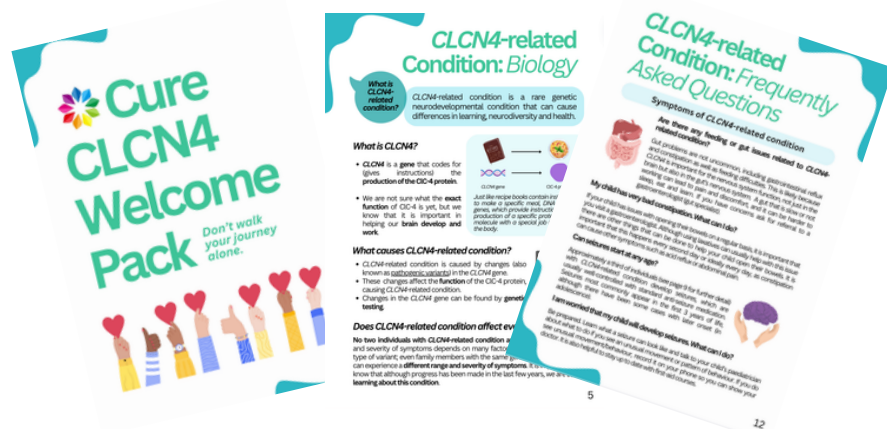


2025 Scientific Conference

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

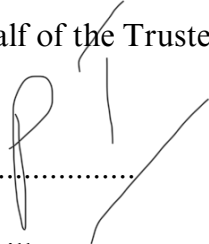
The Trustees' are required under company law to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable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


.....

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			
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	09/06/2026	