

Charity Registration Number

1196811

XLH UK

Annual Report and Unaudited Financial Statements

For the Year to 31 January 2025

XLH UK

Legal and Administrative Information

Trustees

Oliver Gardiner

Sally Hatton

Sarah Mitson

Claire Lewis

Appointed 2 July 2024

Charity number: 1196811

Principal Address:

61A Bridge Street,

Kington

HEREFORDSHIRE

HR5 3DJ

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Trustees Report

Purpose of the Charity

The object of the CIO is the preservation of good health among sufferers of x-linked hypophosphatemia and related disorders by:

- a) supporting research for the public benefit into the causes, prevention, diagnosis and methods of treatment of x-linked hypophosphatemia and related disorders and publishing the useful results of that research;
- b) provision of a support network for families suffering from the effects of x-linked hypophosphatemia and related disorders;
- c) advocating early diagnosis and well-managed treatment of x-linked hypophosphatemia and related disorders.

Summary of main activities

The charity has made progress against all its five strategic objectives.

1. **Awareness & standards of care:** as part of the Rare Bone Collaborative Network, we have been supporting the establishment of a new NHS Rare Disease Care Network (RDCN) of over 22 hospitals across the UK. In partnership with expert clinicians we produced a patient leaflet about burosumab to support those about to start on the treatment.
2. **Access to new treatments:** We contributed evidence as the lead patient group to the Health Technology Assessments for burosumab for adults with XLH, both in England and Wales and in Scotland. The charity welcomes the news that adults with XLH will now be able to access burosumab across the UK.
3. **Information and support:** We held a Community Day in Birmingham in June 2024 which got positive feedback and was well attended. We produce a news digest – XLH UK Navigator – which reaches over half of the UK XLH population and run an online community discussion group called Connect. We provided webinars to inform the community about the NICE decision on adult burosumab and its rollout program.
4. **Research and evidence generation:** Evidence of the impact of XLH on family carers was collected and presented to NICE as part of the ongoing Health Technology Assessments on access to burosumab. In addition, the evidence on Quality of Life for adults with XLH which we collected on UK patients has been scientifically analysed and validated. This has now been published and is available as a white paper in our library.
5. **High performing, sustainable organisation:** XLH UK contributed to an International XLH Alliance meeting with members from many countries coming together to learn from each other. Our charity has a clear strategic plan and regularly reviews its policies, risk management and fundraising plans to enable it to thrive into the future.

Public Benefit

The trustees had regard to the guidance issued by the Charity Commission on the Public Benefit requirement under the Charities Act 2011.

Achievements

In its third year as a Charitable Incorporated Organisation (CIO) the impact of XLH UK (formerly a charitable trust of the same name) has been seen in 2024 across several areas

- strong engagement amongst the patient group, which promotes sharing of information and support for those with XLH and their families.
- partnership with medical and charity partners as a credible representative of the wider XLH community, which allows us to contribute to the formation of better care pathways and treatments.
- opportunities for raising awareness of the condition, which increases understanding of the condition in the wider public and supports fundraising activities.

As a rare genetic condition, XLH is not widely understood or supported. Our mission is to help those with XLH and related disorders through research, support and advocacy, allowing them to access their best care and contribute to society.

XLH UK

Year to 31 January 2025

Financial Review

This year XLH UK received a donations of £2,824 and grants of £10,000 of which £5,000 is restricted to support the development of a clinical pathway for adults with XLH. Our total expenses were £15,824, which meant a deficit of £2,572 was taken from reserves.

Our balance sheet is healthy with net assets standing at £33,743, of which £10,000 is held in an interest bearing fixed term savings account.

The largest part of expenses this year relate to activities supporting research, with funds being used to support the scientific validation of our XLH Quality of Life evidence. The trustees are satisfied with the balance between spend on our different core activities given this year's priorities; for every £10 spent on activities we spent approximately £4 on supporting research, £4 supporting families and £2 on advocacy and awareness.

Reserves Policy

Our policy on reserves was set on 14/4/22 when the trustees decided that modest reserves, sufficient to cover an unforeseen contractual commitment, should be held in our general bank account.

Going concern

The trustees have reviewed the charity's financial position and consider that it remains a going concern and fully able to continue to deliver on its long-term objectives.

Structure, Governance and Management

The charity is constituted as a Charitable Incorporated Organisation (CIO) whose only voting members are its charity trustees.

Trustees are appointed for a term of three years by a resolution passed at a properly convened meeting of the charity trustees. In selecting individuals for appointment as charity trustees, the charity trustees have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

A volunteer induction pack is available and includes our Code of Conduct for volunteers / trustees and details of relevant policies as below.

- Health and Safety Policy
- Safeguarding Policy
- Data Protection Policy
- Risk Management Policy
- Complaints Handling
- Social Media policy
- Expenses Policy
- XLH UK policy on working with the pharmaceutical sector.

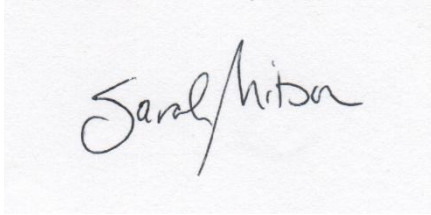
The charity will have no less than three and no more than seven trustees appointed at any one time. Trustees are empowered to recruit contract staff and to enlist volunteers in order to achieve the objects of the charity. Currently the charity has no permanent employees.

XLH UK has a close relationship with **International XLH Alliance (IXLHA)** based on historical shared administration. No grants were made by either charity to each other this financial year.

XLH UK

Year to 31 January 2025

Approved by the Board of Trustees on 21st July 2025 and signed on its behalf by:

A handwritten signature in black ink, reading "Sarah Mitson", is centered within a light gray rectangular box. The signature is written in a cursive, flowing style.

Sarah Mitson
Chair of Trustees

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008, require the trustees to prepare financial statements for each financial year which give a true and fair view of the charity's financial activities during the year and its financial position at the end of the year.

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 (FRS102);
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with applicable law. They are also responsible for safeguarding the assets and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Independent Examiner's Report to the Trustees of the XLH UK For the Year Ended 31 January 2025

I report to the Charity Trustees on my examination of the financial statements of XLH UK (the charity) for the Year to 31 January 2025, which are set out on pages 9-16.

Responsibilities and basis of report

As the trustees of the charity, you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

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

- 1 the accounting records were not kept in accordance with section 130 of the Charities Act; or
- 2 the accounts did not accord with the accounting records; or
- 3 the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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 financial statements to be reached.



22nd July 2025

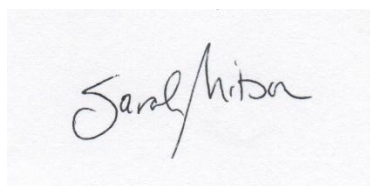
Alison Pierazzini ACA
White Rose Accountancy
10, Hatford
Faringdon
Oxfordshire
SN7 8JF

	Note	Unrestricted funds £	Restricted funds £	Total funds £	Last Year £
Income					
Income and from:					
Donations and legacies	2	7,824	5,000	12,824	16,692
Other	2	428	-	428	1,716
Total Income		8,252	5,000	13,252	18,408
Expenditure					
Charitable activities	3	15,824	-	15,824	24,359
Total Expenditure		15,824	-	15,824	24,359
Net Income/ (Expenditure)		(7,572)	5,000	(2,572)	(5,951)
Net movement in funds		(7,572)	5,000	(2,572)	(5,951)
Reconciliation of funds:					
Total funds brought forward	6-7	36,315	-	36,315	42,266
Total funds carried forward	6-7	28,743	5,000	33,743	36,315

	Notes	Unrestricted funds £	Restricted funds £	Total £	At 31st January 2023 £
Current assets					
Cash at bank and in hand		29,143	5,000	34,143	36,715
Total current assets		29,143	5,000	34,143	36,715
Creditors: amounts falling due within one year	5	400	-	400	400
Net current assets		28,743	5,000	33,743	36,315
Total Net Assets		28,743	5,000	33,743	36,315
Funds of the Charity					
Restricted income funds	7		5,000	5,000	-
Unrestricted funds	6	28,743		33,743	36,315
Total funds		28,743	5,000	33,743	36,315

The financial statements were approved and authorised for issue by the Board of Trustees on 21st July 2025.

Signed on behalf of the board of Trustees by



Sarah Mitson

Chair of Trustees

XLH UK

Notes to the Financial Statements for the for the year to 31 January 2025

1. Accounting policies

1.1 Charity information

XLH UK is a registered charity in the United Kingdom. It is structured as a Charitable Incorporated Organisation. The principal address of the Charity changed on 24th April 2024 to 61 Bridge Street, Kington, HR5 3DJ

1.2 Accounting convention

The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value, and in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), Statement of Recommended Practice: Accounting and Reporting by Charities (Revised 2019) applicable to charities preparing their accounts in accordance with FRS102 ('Charities SORP (FRS102)'), and the Charities Act 2011.

The Charity meets the definition of a public benefit entity under FRS 102

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £

The charity has taken advantage of the exemption in Financial Reporting Standards from the requirement to prepare a cash flow statement on the grounds that it is a small charity.

The principal accounting policies adopted are set out below.

1.3 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.4 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used.

1.5 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Donations and grants are recognised once the charity has been notified of the donation unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

1.6 Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be recovered and is reported as part of the expenditure to which it relates.

1. Accounting policies

(Continued)

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services to beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Volunteers

The value of services provided by volunteers is not incorporated in these financial statements.

Further details of their contribution is set out in note 3 to these financial statements.

1.7 Taxation

The charity is an exempt charity within the meaning of schedule 3 of the Charities 2011 and therefore meets the criteria to be defined as a charity for corporation tax purposes.

1.8 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due. Accrued income and tax recoverable is included at the best estimate of the amounts receivable at the balance sheet date.

1.9 Cash and cash equivalent

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

1.10 Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors are normally recognised at their settlement amount after allowing for any trade discounts due.

1.11 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within

one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

1.12 Critical accounting estimates and judgements

Estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. The Charity makes estimates and assumptions concerning the future. The resulting accounting estimates and assumptions will, by definition, seldom equal the related actual results.

No judgements (apart from those involving estimates) have been made in the process of applying the above accounting policies.

Notes to the Financial Statements for the for the year to 31 January 2025

2. Income

Donations and Legacies

	Unrestricted Income	Restricted income	Total Income	Last Year
	£	£	£	£
Donations	2,824	-	2,824	15,887
Grants	5,000	5,000	10,000	805
Total	7,824	5,000	12,824	16,692

All donation and legacy income in the previous year was unrestricted

Other Income

	Unrestricted Income	Restricted income	Total Income	Last Year
	£	£	£	£
Speaker and other fee Income	428	-	428	1,716
Total	428	-	428	1,716

All other income in the previous year was unrestricted

3. Expenditure

Expenditure on charitable activities

	Unrestricted	Restricted	Total This Year	Unrestricted	Restricted	Total Last Year
	£	£	£	£		£
Family Support	5,145	-	5,145	2,181	5,377	7,558
Research	6,242	-	6,242	-	6,000	6,000
Public Awareness and Advocacy	2,809	-	2,809	-	9,623	9,623
General Administration	1,628	-	1,628	1,178	-	1,178
Total	15,824	-	15,824	3,359	21,000	24,359

XLH UK

Notes to the Financial Statements for the for the year to 31 January 2025

Included in the expenditure on charitable activities are:

Fees payable to the Independent Examiner

	This Year £	Last Year £
For examination of the accounts	400	400
Total	400	400

Staff Numbers

There were no staff employed by the Charity during the year.

Volunteers

The charity is very grateful for the work carried out by a volunteer who helps run the support group XLH Connect.

4.Trustees and Key Management Personnel

None of the trustees (or any persons connected with them) received any remuneration or benefits, from the charity during the year.

3 of the trustees incurred travel and subsistence costs during the period totalling £442.

5. Creditors: Amounts falling due within one year

	This Year	Last Year
	£	
Accruals and deferred income	400	400
Total	400	400

All creditors were unrestricted.

XLH UK

Notes to the Financial Statements for the for the year to 31 January 2025

6. Unrestricted Funds

This Year

	Balance at 1 February 2024	Income	Expenditure	Transfers	Balance at 31 January 2025
	£	£	£	£	£
General Fund	36,315	8,252	(15,824)	-	28,743
Total	36,315	8,252	(15,824)	-	28,743

Last year

	Balance at 1 February 2023	Income	Expenditure	Transfers	Balance at 31 January 2024
	£	£	£	£	£
General Fund	21,266	18,408	(3,359)	-	36,315
Total	21,266	18,408	(3,359)	-	36,315

7. Restricted Funds

This Year

	Balance at 1 February 2024	Income	Expenditure	Transfers	Balance at 31 January 2025
	£	£	£	£	£
Other restricted Funds	-	5,000	-	-	5,000
	-	5,000	-	-	5,000

Last Year

	Balance at 1 February 2023	Income	Expenditure	Transfers	Balance at 31 January 2024
	£	£	£	£	£
Other restricted Funds	21,000	-	(21,000)	-	-
	21,000	-	(21,000)	-	-

Analysis of Net Assets between Funds

	At 31 January 2025			At 31 January 2024
	Unrestricted	Restricted	Total	
	£	£	£	£
Current Assets	29,143	5,000	34,143	36,715
Current Liabilities	(400)	-	(400)	(400)
	28,743	5,000	33,743	36,315

All net assets at 31 January 2024 were unrestricted.

8. Related party transactions

There have been no related party transactions during the financial year.