

**Charity Registration Number**

**1196811**

**XLH UK**

**Annual Report and Unaudited Financial Statements**

**For the Year to 31 January 2024**

**XLH UK**

**Legal and Administrative Information**

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**Trustees**

Oliver Gardiner

Sally Hatton

Sarah Mitson

**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. Together we have developed a networked service model for care of adults with rare bone conditions in England.
2. **Access to new treatments:** we contributed to Health Technology Assessments for burosumab for adults, both in England and Wales and in Scotland. The charity welcomes the news that adults with XLH will now be able to access burosumab in Scotland. When NICE announced draft guidance that burosumab would not be available on the NHS for adults in England, the charity mobilised the community to submit further evidence to counter 'uncertainties' that NICE articulated.
3. **Information and support:** We have totally upgraded our website this year, with updated software and greatly enriched content. Our social media activity has increased and we were successful in achieving BBC regional coverage of our call for burosumab to be recommended by NICE. We held a patient family day in Bristol in May 2023 which got positive feedback and engagement from a number of new volunteers. We started an online support group, called XLH Connect, which allows members of the community to discuss their shared experience of living with XLH.
4. **Research and evidence generation:** We built evidence on Quality of Life for adults with XLH based on an extensive survey of UK patients and have commissioned the results of the survey to be prepared and published as an Open Source white paper. This evidence has been presented to the Scottish Medical Consortium and to NICE as part of the ongoing Health Technology Assessments on access to burosumab.
5. **High performing, sustainable organisation:** XLH UK and International XLH Alliance have achieved operational independence and clarity about their respective areas of focus. This year XLH UK updated the risk register and added a Social Media policy and an Equity, Diversity and Inclusion policy as a result of the annual strategic review.

### **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 second year as a Charitable Incorporated Organisation (CIO) the impact of the increased activity of XLH UK (formerly a charitable trust of the same name) has been seen in 2023 across several areas

- increased engagement amongst the patient group, which in turn leads to increased sharing of information and support for those with XLH and their families.
- increased confidence of medical and charity partners that we are credible representatives of the wider XLH community, which allows us to contribute to the formation of better care pathways and treatments.
- increased 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

## **XLH UK**

### **Year to 31 January 2024**

related disorders through research, support and advocacy, allowing them to access their best care and contribute to society.

#### **Financial Review**

This year XLH UK received a significant uplift in donations of £15,887 thanks to a team fundraiser by the Battleborn running group from Northern Ireland. Fee income of £1,716 and a small grant from Acaster Lloyd resulted in total income of £18,408. Our total expenses were £24,359, which meant a deficit of £5,951 was taken from reserves.

During the year we completed the activities relating to the restricted grant from Kyowa Kirin in YE 31/1/23. Our balance sheet is healthy with net assets standing at £36,315, with no designations or restrictions.

The largest part of expenses this year relate to activities supporting advocacy and public awareness, in a year when the website had a major upgrade. 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 advocacy and awareness, £3 supporting families and £3 supporting research.

#### **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.

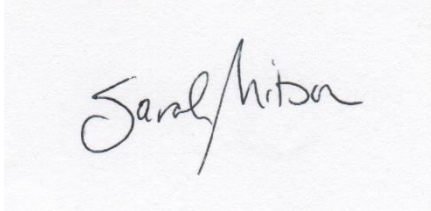
XLH UK has a close relationship with **International XLH Alliance (IXLHA)** based on historical shared administration. No grants were made by either charity to each other this financial year, but a write-down of £346.14 of XLH UK debt

## **XLH UK**

### **Year to 31 January 2024**

to IXLHA was agreed by both parties, in order to clear outstanding balances arising from the separation of assets between the two charities on separation in the previous financial year.

Approved by the Board of Trustees on 18<sup>th</sup> June 2024 and signed on its behalf by:

A rectangular box containing a handwritten signature in black ink. The signature is written in a cursive style and appears to read "Sarah Mitson".

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 2024

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I report to the Charity Trustees on my examination of the financial statements of XLH UK (the charity) for the Year to 31 January 2024, 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.



Date: 18<sup>th</sup> June 2024

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



**XLH UK****Statement of Financial Activities for the Year to 31 January 2024**

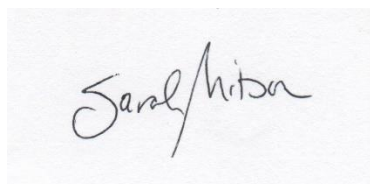
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	Note	Unrestricted funds £	Restricted funds £	Total funds £	Last Year £
<b>Income</b>					
<b>Income and from:</b>					
Donations and legacies	2	16,692	-	16,692	23,082
Other	2	1,716	-	1,716	-
<b>Total Income</b>		<b>18,408</b>	<b>-</b>	<b>18,408</b>	<b>23,082</b>
<b>Expenditure</b>					
Charitable activities	3	3,359	21,000	24,359	27,539
<b>Total Expenditure</b>		<b>3,359</b>	<b>21,000</b>	<b>24,359</b>	<b>27,539</b>
<b>Net Income/ (Expenditure)</b>		<b>15,049</b>	<b>(21,000)</b>	<b>(5,951)</b>	<b>(4,457)</b>
<b>Net movement in funds</b>		<b>15,049</b>	<b>(21,000)</b>	<b>(5,951)</b>	<b>(4,457)</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward	7-8	21,266	21,000	42,266	46,723
<b>Total funds carried forward</b>	7-8	<b>36,315</b>	<b>-</b>	<b>36,315</b>	<b>42,266</b>

	Notes	Unrestricted funds £	Restricted funds £	Total £	At 31st January 2023 £
<b>Current assets</b>					
Debtors	5	-	-	-	22,695
Cash at bank and in hand		36,715	-	36,715	19,971
<b>Total current assets</b>		<b>36,715</b>	<b>-</b>	<b>36,715</b>	<b>42,666</b>
<b>Creditors: amounts falling due within one year</b>					
	6	400	-	400	400
<b>Net current assets</b>		<b>36,315</b>	<b>-</b>	<b>36,315</b>	<b>42,266</b>
<b>Total Net Assets</b>		<b>36,315</b>	<b>-</b>	<b>36,315</b>	<b>42,266</b>
<b>Funds of the Charity</b>					
Restricted income funds	8		-	-	21,000
Unrestricted funds	7	36,315		36,315	21,266
<b>Total funds</b>		<b>36,315</b>	<b>-</b>	<b>36,315</b>	<b>42,266</b>

The financial statements were approved and authorised for issue by the Board of Trustees on 18<sup>th</sup> June 2024.

Signed on behalf of the board of Trustees by



**Sarah Mitson**

**Chair of Trustees**

**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 24<sup>th</sup> 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.

# XLH UK

## Notes to the Financial Statements for the for the year to 31 January 2024

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### 2. Income

#### Donations and Legacies

	Unrestricted Income	Restricted income	Total Income	Last Year
	£	£	£	£
Donations	15,887	-	15,887	2,082
Grants	805	-	805	21,000
<b>Total</b>	<b>16,692</b>	<b>-</b>	<b>16,692</b>	<b>23,082</b>

#### Other Income

	Unrestricted Income	Restricted income	Total Income	Last Year
	£	£	£	£
Speaker and other fee Income	1,716	-	1,716	-
<b>Total</b>	<b>1,716</b>	<b>-</b>	<b>1,716</b>	<b>-</b>

### 3. Expenditure

#### Expenditure on charitable activities

	Unrestricted	Restricted	Total This Year	Last Year
	£	£	£	£
Family Support	2,181	5,377	7,558	5,552
Research	-	6,000	6,000	16,185
Public Awareness and Advocacy	-	9,623	9,623	5,020
General Administration	1,178	-	1,178	782
<b>Total</b>	<b>3,359</b>	<b>21,000</b>	<b>24,359</b>	<b>27,539</b>

All expenditure in the previous year were unrestricted.

# XLH UK

## Notes to the Financial Statements for the for the year to 31 January 2024

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Included in the expenditure on charitable activities are:

### Fees payable to the Independent Examiner

	<b>This Year £</b>	<b>Last Year £</b>
For examination of the accounts	400	400
<b>Total</b>	<b>400</b>	<b>400</b>

### 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 £651.

## 5. Debtors and Prepayments

	<b>This Year £</b>	<b>Last Year</b>		<b>Total Last Year £</b>
		<b>Unrestricted £</b>	<b>Restricted £</b>	
Other Debtors	-	1,695	21,000	<b>22,695</b>
<b>Total</b>	<b>-</b>	<b>1,695</b>	<b>21,000</b>	<b>22,695</b>

## 6. Creditors: Amounts falling due within one year

	<b>This Year £</b>	<b>Last Year</b>
Accruals and deferred income	400	400
<b>Total</b>	<b>400</b>	<b>400</b>

All creditors were unrestricted.

# XLH UK

## Notes to the Financial Statements for the for the year to 31 January 2024

### 7. Unrestricted Funds

#### This 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	<b>21,266</b>	<b>18,408</b>	<b>(3,359)</b>	-	<b>36,315</b>

#### Last Period

	Balance at 28 November 2021	Income	Expenditure	Transfers	Balance at 31 January 2023
	£	£	£	£	£
General Fund	46,723	2,082	(27,539)	-	21,266
Total	<b>46,723</b>	<b>2,082</b>	<b>(27,539)</b>	-	<b>21,266</b>

### 8. Restricted Funds

#### This 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)	-	-

#### Last Period

	Balance at 28 November 2021	Income	Expenditure	Transfers	Balance at 31 January 2023
	£	£	£	£	£
Other restricted Funds	-	21,000	-	-	21,000
	-	21,000	-	-	21,000

### Analysis of Net Assets between Funds

	At 31 January 2024	At 31 January 2023		
		Unrestricted	Restricted	Total
	£	£	£	£
Current Assets	36,715	21,666	21,000	42,666
Current Liabilities	(400)	(400)	-	(400)
	<b>36,315</b>	<b>21,266</b>	<b>21,000</b>	<b>42,266</b>

All net assets at 31 January were unrestricted.

### 9. Related party transactions

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