

**Charity Registration Number**

**1196811**

**XLH UK**

**Annual Report and Unaudited Financial Statements**

**For the Period from 29<sup>th</sup> November 2021 to 31**

**January 2023**

**XLH UK**

**Legal and Administrative Information**

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**Trustees**

Oliver Gardiner	Appointed 29 November 2021
Sally Hatton	Appointed 29 November 2021
Sarah Mitson	Appointed 29 November 2021

**Charity number:** 1196811

**Principal Address:**

21 Providence Street  
Greenhithe  
Wallingford  
DA9 9AA

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## **XLH UK**

**Period from 29 November 2021 to 31 January 2023**

## **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: we teamed up with International XLH Alliance, attending the medical symposium in Dublin and promoting the findings of the white paper on best standards of care.
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 recent news that adults with XLH will now be able to access burosumab in Scotland.
3. Information and support: we improved the information available on our website and consolidated our social media presence. We held a patient family day in Manchester in October 2022 which got positive feedback and engagement from a number of new volunteers. We produced a newsletter – XLH UK Navigator - which reaches over half of the UK XLH population.
4. Research and evidence generation: We commissioned a series of depth qualitative studies into the lived experience of XLH, leading to the creation of four compelling patient stories that cover the varied challenges of XLH. In addition, evidence presented to the Scottish Medical Consortium was based on an extensive survey of UK patients, designed in partnership with Metabolic Support UK.
5. High performing, sustainable organisation: XLH UK and International XLH Alliance have achieved operational independence and clarity about their respective areas of focus. The charity has developed and shared a strategic plan with volunteers. This year XLH UK also reviewed 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 first 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 2022 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 related disorders through research, support and advocacy, allowing them to access their best care and contribute to society.

## **XLH UK**

**Period from 29 November 2021 to 31 January 2023**

### **Financial Review**

This year XLH UK received donations of £2,082 and a grant from Kyowa Kirin of £21,000 to support patient events and awareness building for the charity. Our total expenses were £27,539, which meant a deficit of £4,457 was taken from reserves.

Our balance sheet is healthy as we carried over reserves from the charitable trust built from two years of limited activity due to the pandemic. Net assets currently stand at £42,266, of which £21,000 is restricted as described above.

The largest part of expenses relate to activities supporting research, particularly the commissioning of patient stories of lived experience. Other expenses divide equally between activities supporting families and building public awareness / advocacy.

### **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
- Expenses Policy
- XLH UK policy on working with the pharmaceutical sector.
- Complaints Handling

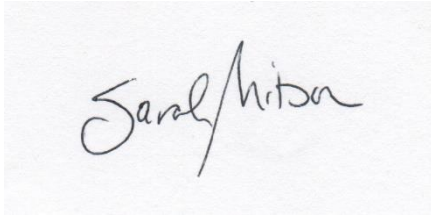
The charity will have no less than three and no more than seven trustees appointed at any one time. Trustees are empowered to recruit contract staff and to enlist volunteers in order to achieve the objects of the charity. Currently the charity has no permanent employees.

## XLH UK

### Period from 29 November 2021 to 31 January 2023

XLH UK has a close relationship with **International XLH Alliance (IXLHA)** based on historical shared administration. XLH UK are contributing members of this independent charity and donated £5,000 to IXLHA in this financial year as a contribution to the costs of the international medical symposium held on 1<sup>st</sup> July 2022.

Approved by the Board of Trustees on 10th October 2023 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Sarah Mitson', is centered within a rectangular box.

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 March 2022**

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I report to the Charity Trustees on my examination of the financial statements of XLH UK (the charity) for the period from 29 November 2021 to 31 January 2023, 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: 10<sup>th</sup> October 2023

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

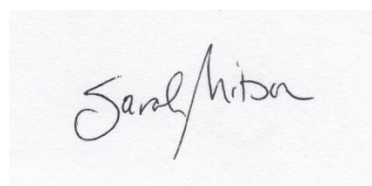


	Note	Unrestricted funds £	Restricted funds £	Total funds £	Last Year £
<b>Income</b>					
<b>Income and from:</b>					
Donations and legacies	2	2,082	21,000	23,082	4,930
Other		-	-	-	1,015
<b>Total Income</b>		<b>2,082</b>	<b>21,000</b>	<b>23,082</b>	<b>5,945</b>
<b>Expenditure</b>					
Charitable activities	3	27,539	-	27,539	464
<b>Total Expenditure</b>		<b>27,539</b>	<b>-</b>	<b>27,539</b>	<b>464</b>
<b>Net Income/ (Expenditure)</b>		<b>(25,457)</b>	<b>21,000</b>	<b>(4,457)</b>	<b>5,481</b>
<b>Net movement in funds</b>		<b>(25,457)</b>	<b>21,000</b>	<b>(4,457)</b>	<b>5,481</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward	7-8	46,723	-	46,723	41,242
<b>Total funds carried forward</b>	<b>7-8</b>	<b>21,266</b>	<b>21,000</b>	<b>42,266</b>	<b>46,723</b>

	Notes	Unrestricted funds £	Restricted funds £	Total £	At 31st January 2022 £
<b>Current assets</b>					
Debtors	5	1,695	21,000	22,695	
Cash at bank and in hand		19,971		19,971	47,417
<b>Total current assets</b>		<b>21,666</b>	<b>21,000</b>	<b>42,666</b>	<b>47,417</b>
<b>Creditors: amounts falling due within one year</b>	6	400	-	400	694
<b>Net current assets</b>		<b>21,266</b>	<b>21,000</b>	<b>42,266</b>	<b>46,723</b>
<b>Total Net Assets</b>		<b>21,266</b>	<b>21,000</b>	<b>42,266</b>	<b>46,723</b>
<b>Funds of the Charity</b>					
Restricted income funds	8		21,000	21,000	
Unrestricted funds	7	21,266		21,266	46,723
<b>Total funds</b>		<b>21,266</b>	<b>21,000</b>	<b>42,266</b>	<b>46,723</b>

The financial statements were approved and authorised for issue by the Board of Trustees on 10<sup>th</sup> October 2023

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 is 21 Providence Road, Greenhithe, DA9 9AA.

### **1.2 1 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.

**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.

**1.13 Accounting period and comparative information**

The Charitable Incorporated Organisation was registered with the Charity Commission on the 29<sup>th</sup> November 2021 therefore the accounts cover the 14 month period from that date to 31<sup>st</sup> January 2023.

The comparative figures cover the year from 1<sup>st</sup> February 2021 to 31<sup>st</sup> January 2022 . During this period the Charity operated as part of the Charitable Trust International XLH Alliance, sharing administration costs although the charitable activities remained separate.

# XLH UK

## Notes to the Financial Statements for the for the period from 29 November 2021 to 31 January 2023

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### 2. Income

#### Donations and Legacies

	Unrestricted Income	Restricted income	Total Income	Last Year
	£	£	£	£
Donations	2,082		2,082	
Grants		21,000	21,000	4,930
<b>Total</b>	<b>2,082</b>	<b>21,000</b>	<b>23,082</b>	<b>4,930</b>

### 3. Expenditure

#### Expenditure on charitable activities

	Total For Period	Last Year
	£	£
Family Support	5,552	
Research	16,185	
Public Awareness and Advocacy	5,020	
General Administration	782	464
<b>Total</b>	<b>27,539</b>	<b>464</b>

All expenditure was unrestricted.

Included in the expenditure on charitable activities are:

#### Fees payable to the Independent Examiner

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

#### Staff Numbers

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

## Notes to the Financial Statements for the for the period from 29 November 2021 to 31 January 2023

### 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 period.

2 of the trustees incurred travel and subsistence costs during the period totalling £465.

### 5. Debtors and Prepayments

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

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

	This Period	Last Year
	£	£
Accruals and deferred income	400	694
<b>Total</b>	<b>400</b>	<b>694</b>

All creditors were unrestricted.

### 7. Unrestricted Funds

#### This Period

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

#### Last Year

	Balance at 1 February 2021	Income	Expenditure	Transfers	Balance at 31 January 2022
	£	£	£	£	£
General Fund	41,242	5,945	(464)	-	46,723
<b>Total</b>	<b>41,242</b>	<b>5,945</b>	<b>(464)</b>	<b>-</b>	<b>46,723</b>

### 8. Restricted Funds

#### This Period

	Balance at 28 November 2021	Income	Expenditure	Transfers	Balance at 31 January 2023
	£	£	£	£	£
Other restricted Funds	-	21,000	-	-	21,000
<b>Total</b>	<b>-</b>	<b>21,000</b>	<b>-</b>	<b>-</b>	<b>21,000</b>

There were no restricted funds movements in the prior year.

# XLH UK

## Notes to the Financial Statements for the for the period from 29 November 2021 to 31 January 2023

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### Analysis of Net Assets between Funds

	At 31 January 2023			At 31 <sup>st</sup> January 2022
	Unrestricted	Restricted	Total	Unrestricted
	£	£	£	£
Current Assets	21,666	21,000	42,666	47,417
Current Liabilities	(400)	-	(400)	(694)
	<u>21,266</u>	<u>21,000</u>	<u>42,266</u>	<u>46,723</u>

There were no restricted funds in the prior year.

### 9. Related party transactions

During the year the charity made a contribution of £5,000 towards the costs of a medical symposium to an independent but closely affiliated charity International XLH Alliance.

There was no outstanding balance relating to this transaction at 31st January 2023.