

# International XLH Alliance

England & Wales · Charity number 1182964

## Details

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**Other names** XLH UK

**Status** Registered

**Legal form** Trust

**Registered** 2019-04-12

**Register** [View on the Charity Commission register](#)

## Contact

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**Address** 28 Tunbury Avenue  
Chatham  
Kent  
ME5 9EJ

**Phone** 07905115944

**Email** [contact@xlhalliance.org](mailto:contact@xlhalliance.org)

**Website** [xlhalliance.org](http://xlhalliance.org)

## Activities

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**Objects:** 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.

**Activities:** To unite and amplify the patient voice by supporting x-linked hypophosphataemia (XLH) groups worldwide and to set a global standard of care and research that ensures all patients receive the care that meets their individual needs.

## Classification

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- **How:** Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

## Geography

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- Australia
- Austria
- Belgium
- Brazil
- Bulgaria
- Canada
- Chile
- Denmark
- Finland
- France
- Germany
- Guernsey
- Hong Kong
- Hungary
- India
- Ireland
- Isle Of Man
- Israel
- Italy
- Japan
- Jersey
- Netherlands
- Northern Ireland
- Norway
- Portugal
- Scotland
- Spain
- Sweden
- Switzerland
- United States
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-01-31	£690	£4,390	-	-
2024-01-31	£690	£4,390	-	-
2023-01-31	£82,141	£66,295	-	-
2022-01-31	£7,531	£1,646	-	-
2021-01-31	£66,727	£578	-	-

## Trustees

Name	Role	Appointed
<b>Oliver Gardiner</b>	Chair	2017-11-18
Sally Marianne Shaw		2020-11-29
Shannon Sharp		2022-06-30

**International XLH Alliance**

England & Wales - Charity number 1182964

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# Accounts

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**Charity Registration Number**

**1182964**

**International XLH Alliance**

**Annual Report and Unaudited Financial Statements**

**For the Year Ended 31 January 2023**

**International XLH Alliance**  
**Legal and Administrative Information**

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**Trustees**

Oliver Gardiner

Sally Hatton

Shannon Sharp

Appointed 30<sup>th</sup> June 2022

Anne Papé

Resignation 14<sup>th</sup> December 2022

**Charity number:** 1182964

**Principal Address:**

21 Providence Street

Greenhithe

Wallingford

DA9 9AA

**International XLH Alliance**  
**Year Ended 31 January 2023**

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# International XLH Alliance

## Year Ended 31 January 2023

### Trustees Report

#### Purpose of the Charity

The object of the Charity is the preservation of good health among sufferers of x-linked hypophosphatemia and related disorders by uniting and amplifying the patient voice, by supporting x-linked hypophosphataemia (XLH) groups worldwide and to set a global standard of care and research that ensures all patients receive the care that meets their individual needs.

#### Summary of main activities

As referred to in the previous financial year, from February 2022 XLH UK has separated out from the International XLH Alliance in the form of a new distinct organisation. From February 2022, this charity changed its name to the International XLH Alliance. This is to allow IXLHA to continue to grow its international network of patient groups without compromising XLH UK's focus on the XLH community in the UK.

The International XLH Alliance is the group that brings together XLH patient organisations from around the world. XLH UK is a founding member of the International XLH Alliance, and it is a strong, mutually beneficial relationship.

In the last 12 months the charity has made good progress against its strategic objectives.

1. Awareness & standards of care: we teamed up with XLH UK, 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.
3. Information and support: we improved the information available on our website and consolidated our social media presence.
4. High performing, sustainable organisation: International XLH Alliance and XLH UK and have achieved operational independence and clarity about their respective areas of focus. The charity has developed and shared a strategic plan with volunteers.

#### Public Benefit

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

#### Contribution made by volunteers

The Charity is extremely grateful for the contributions made volunteers. Their support in scientific research, events organisation, communications, fundraising and finance has ensured International XLH Alliance's ongoing success.

#### Achievements

From its activities during the year the charity achieved the following:

- Successfully organised the medical symposium in Dublin.
- 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.

## **International XLH Alliance**

### **Year Ended 31 January 2023**

#### **Financial Review**

This year international XLH Alliance received grants and donations of £82,141. This included restricted grants of £61,080 made to fund the Symposium held in Dublin. The majority of the expenditure for the year of £65,500, comprised the costs of research and organisation of the symposium.

International XLH Alliance is in a good financial position at the end of the year with net assets of £80,998. This consists of cash less current creditors. Its main creditor (£22,695) is a related charity being XLH UK, from whom it split in February 2022.

#### **Reserves Policy**

The Charity's reserve policy requires 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 Trust. It was registered on 12 April 2019 under the name XLH UK, with its name being changed to International XLH Alliance in February 2022 when the UK part of the Charity was registered as a separate CIO .

#### **Trustee selection method**

Trustee selection is in accordance with the charity's governing document.

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 charitable trust.

The policy and operating decisions of the charity rest with the trustees' who meet regularly to monitor the activities of the charity.

Approved by the Board of Trustees on 30<sup>th</sup> November 2023 and signed on its behalf by:

*Oliver Gardiner*

Oliver Gardiner  
Chair of Trustees

**International XLH Alliance**  
**Year Ended 31 January 2023**

**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 International XLH Alliance For the Year Ended 31 January 2023

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I report to the Charity Trustees on my examination of the financial statements of International XLH Alliance (the charity) for the year ended 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: 30<sup>th</sup> November 2023

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

**International XKH Alliance**  
**Statement of Financial Activities for the Year Ended 31 January 2023**

	Note	Unrestricted funds £	Restricted funds £	Total funds £	Last Year £
<b>Income</b>					
<b>Income and from:</b>					
Donations and legacies	2	21,061	61,080	82,141	1,587
<b>Total Income</b>		<b>21,061</b>	<b>61,080</b>	<b>82,141</b>	<b>1,587</b>
<b>Expenditure</b>					
Charitable activities	3	5,215	61,080	66,295	1,182
<b>Total Expenditure</b>		<b>5,215</b>	<b>61,080</b>	<b>66,295</b>	<b>1,182</b>
<b>Net Income/ (Expenditure)</b>		<b>15,846</b>	<b>-</b>	<b>15,846</b>	<b>405</b>
<b>Net movement in funds</b>		<b>15,846</b>	<b>-</b>	<b>15,846</b>	<b>405</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward	6-7	65,152	-	65,152	64,747
<b>Total funds carried forward</b>	6-7	<b>80,998</b>	<b>-</b>	<b>80,998</b>	<b>65,152</b>

**International XKH Alliance**  
**Balance Sheet at 31 January 2023**

	Notes	Unrestricted funds £	Restricted funds £	Total £	At 31st January 2022 £
<b>Current assets</b>					
Cash at bank and in hand		106,045	-	106,045	66,390
<b>Total current assets</b>		<b>106,045</b>	<b>-</b>	<b>106,045</b>	<b>66,390</b>
<b>Creditors: amounts falling due within one year</b>	<b>5</b>	25,047	-	25,047	1,238
<b>Net current assets</b>		<b>80,998</b>	<b>-</b>	<b>80,998</b>	<b>65,152</b>
<b>Total Net Assets</b>		<b>80,998</b>	<b>-</b>	<b>80,998</b>	<b>65,152</b>
<b>Funds of the Charity</b>					
Restricted income funds	<b>7</b>	-	-	-	-
Unrestricted funds	<b>6</b>	80,998	-	<b>80,998</b>	65,152
<b>Total funds</b>		<b>80,998</b>	<b>-</b>	<b>80,998</b>	<b>65,152</b>

The financial statements were approved and authorised for issue by the Board of Trustees on 30<sup>th</sup> November 2023

Signed on behalf of the board of Trustees by

**Oliver Gardiner**

**Chair of Trustees**

*Oliver Gardiner*

30/11/2023

## **International XKH Alliance**

### **Notes to the Financial Statements for the for the year ended 31 January 2023**

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#### **1. Accounting policies**

##### **1.1 Charity information**

International XLH Alliance is a registered charity in the United Kingdom. It is structured as a Charitable Trust. 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**

In prior years the UK element of the charity operated as part of the charitable trust and although their activities were separate, they shared administrative costs.

On 29<sup>th</sup> November 2021 the UK charity was registered with the Charity Commission as a CIO, XLH UK. The comparative figures for the Charitable Trust for the year to 31<sup>st</sup> January 2021 have therefore been restated to exclude the activities of XLH UK.

## International XKH Alliance

### Notes to the Financial Statements for the for the year ended 31 January 2023

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#### 2. Income

##### Donations and Legacies

	Unrestricted Income	Restricted income	Total Income	Last Year
	£	£	£	£
Donations	10	-	10	1,026
Grants	21,051	61,080	82,131	561
<b>Total</b>	<b>21,061</b>	<b>61,080</b>	<b>82,141</b>	<b>1,587</b>

All of last year's income was unrestricted.

#### 3. Expenditure

##### Expenditure on charitable activities

	Unrestricted	Restricted	Total	Last Year
	£	£	£	£
Research	4,468	61,080	65,548	-
General Administration	747	-	747	1,182
<b>Total</b>	<b>5,215</b>	<b>61,080</b>	<b>66,295</b>	<b>1,182</b>

All of last year's expenditure was unrestricted.

Included in the expenditure on charitable activities are:

##### Fees payable to the Independent Examiner

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

##### Staff Numbers

There were no staff employed by the Charity during the current or prior year.

## International XKH Alliance

### Notes to the Financial Statements for the for the year ended 31 January 2023

#### Volunteers

The charity is reliant on the support of its volunteers. The number of volunteers contributing towards the work of the charity during the year were:

Finance	1
Events organisation	8
Scientific support	4
Communications	10
Fundraising	3
<b>Total</b>	<u>26</u>

#### 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 current or prior year.

1 of the trustees incurred travel and subsistence costs during the period totalling £191.

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

	This Year	Last Year
	£	
Other Creditors	22,695	-
Accruals and deferred income	2,352	1,238
<b>Total</b>	<u><b>25,047</b></u>	<u><b>1,238</b></u>

All creditors in both years were unrestricted.

#### 6. Unrestricted Funds

##### This Year

	Balance at 1 February 2022	Income	Expenditure	Transfers	Balance at 31 January 2023
	£	£	£	£	£
General Fund	65,152	21,061	(5,215)	-	<b>80,998</b>
<b>Total</b>	<u><b>65,152</b></u>	<u>21,061</u>	<u>(5,215)</u>	<u>-</u>	<u><b>80,998</b></u>

##### Last Year

	Balance at 1 February 2021	Income	Expenditure	Transfers	Balance at 31 January 2022
	£	£	£	£	£
General Fund	64,747	1,587	(1,182)	-	<b>65,152</b>
<b>Total</b>	<u>64,747</u>	<u>1,587</u>	<u>(1,182)</u>	<u>-</u>	<u><b>65,152</b></u>

## International XKH Alliance

### Notes to the Financial Statements for the for the year ended 31 January 2023

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#### 7. Restricted Funds

##### This Year

	Balance at 1 February 2022	Income	Expenditure	Transfers	Balance at 31 January 2023
	£	£	£	£	£
Other restricted Funds	-	61,080	(61,080)	-	-
	-	61,080	(61,080)	-	-

There were no restricted funds movements in the prior year.

#### 8. Analysis of Net Assets between Funds

	At 31 January 2023			At 31 <sup>st</sup> January 2022
	Unrestricted	Restricted	Total	Total
	£	£	£	£
Current Assets	106,045	-	106,045	66,390
Current Liabilities	(25,047)	-	(25,047)	(1,238)
	80,998	-	80,998	65,152

There were no restricted funds in the prior year.

#### 9. Related party transactions

During the year the charity received a contribution of £5,000 towards the costs of the medical symposium from an independent but closely affiliated charity XLH UK.

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

**International XLH Alliance**

England & Wales - Charity number 1182964

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# Accounts

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## Trustees' Annual Report for the period

From 01/02/2020      Period start date    To 31/01/2021      Period end date

Charity name: XLH UK

Charity registration number: 1182964

## Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	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 the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.		<b>XLH UK</b>  XLH UK exists to inform and support XLH patients internationally, with a primary focus on those in the UK. XLH UK participated in the first of many Rare Bone Alliance meetings in collaboration with the Brittle Bone Society, Fibrous Dysplasia Society UK and Soft Bones UK in order to improve services for those with rare bone disorders. These include clearer guidance on disability assessments, improving diagnosis through GPs and new-born health visitor training information as well as focusing on transition care.  XLH UK assisted with further clarifications with health care assessors in Merchants House of Glasgow for the Scottish Medicines Consortium. We are delighted to have been

involved in the decision making that ultimately recommends new therapy for use with children with XLH in Scotland.

XLH UK collaborated with Ando (the Portuguese patient organisation that supports those with Achondroplasia and XLH) and the International XLH Alliance on an informative XLH video that is now available for those to learn more about XLH in a video format.

In a response to further celebrate the Rare Disease Day, we collaborated with Media Planet UK to work with them on an article for the New Scientist magazine and online which allowed XLH UK to highlight to a new audience the complexities of treatment and the need for early and routine care.

Sally Hatton shared her unique perspective on how her challenges with XLH are often with other rare diseases are sometimes not immediately obvious. The #IAmNumber17 campaign provided a critical platform for the patient voice allowing those with rare diseases to be heard. The participation involved both online, printed, and formal launch at an exhibition in London.

XLH UK played a key role in bringing together clinicians, patient group leaders and patients to launch the paper on the unrecognised burden of XLH in adults through a webinar and streamed for free online.

This event provided information on the unmet needs of adults with XLH, and gave evidence on current and future approaches to treatment and research in adult care. Our stakeholders debated ideas to support our call to action to improve the lives of adults with XLH.

XLH UK held a session on XLH in collaboration with Metabolic Support UK where we had an opportunity to talk to patients, carers, and families on the vision of XLH UK and the key challenges and strategies.

**International XLH Alliance**

		<p>The International XLH Alliance is an informal group that brings together XLH patient organisations from around the world. XLH UK is a founding member of the International XLH Alliance.</p> <p>It amplifies the patient voice of XLH and related disorders, to set a global multi-disciplinary standard of care and research that could not be achieved independently, to ensure that all patients' management is the same.</p> <p>In January 2020, XLH UK opened a new account within XLH UK bank account that is solely for restricted funds for the purpose of International XLH Alliance activities.</p>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	In planning the activities of the charity the trustees' have regard to the guidance on public benefit issued by the Charity Commission.

#### **Additional information (optional)**

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	N/A
Policy on social investment including program related investment	Para 1.38	N/A
Contribution made by volunteers	Para 1.38	Special contributions have been made by Dr Kassim Javaid, Dr Moira Cheung, Prof Richard Keen, Dr Nick Shaw, Sebastian Gardiner, Jean Mossman, Inês Alves, Dr. Karl Insogna, Dr. Peter Kamenicky, Pol

		Harvengt, Eric Low, Tenna Toft Sylvest, Elizabeth Olear and Ingunn Westerheim.
Other		XLH UK policy on working with pharmaceutical and medical device companies:  <a href="https://xlhuk.org/xlh-uk-policy-on-working-with-pharmaceutical-and-medical-device-companies/">https://xlhuk.org/xlh-uk-policy-on-working-with-pharmaceutical-and-medical-device-companies/</a>

## 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	<p>2020 saw a critical time for XLH UK to represent the patients, their families and carers in two key areas 1) working with healthcare assessors to ensure the patient voice is heard as they better understand the impact XLH has on individuals and the family unit. Healthcare assessors in Ireland now recommend burosumab for children and young adults with growing bones changing the lives of those individuals mitigating the need for complex surgeries and many of the difficulties that adults with XLH live with. 2) With the challenging and complex nature to adjust our way of working due to COVID-19 restrictions, we moved with a greater emphasis to working collaboratively, learning from other organisations and holding digital based events.</p> <p>International XLH Alliance successfully applied for a key unrestricted grant that it received in August 2020 which will be critical for the International XLH Alliance to execute on its objectives and promise that will continue to benefit society as a whole.</p>

## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Despite the global pandemic (COVID-19), the charity has had a critical membership growth year as well as being involved in key strategic planning. During the year ended 31.01.2021 its activity has been confined to
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		strategy and organising. During the year it was fortunate to receive £64,864 in unrestricted grants from Kyowa Kirin International. These funds have been designated for the International XLH Alliance use. The result has been a surplus of Income over Expenditure of £66,149 for the year and a closing cash of £106,943.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	Being a new charity its current policy is to hold its cash reserves in a normal current bank account. However, as it develops its strategic plan in line with objectives it may seek to hold cash reserves in normal bank deposit accounts with the lowest risk possible. The charity has a minimum risk possible policy.  The charity is holding £105,989 in accumulated reserves and is developing plans for its use in the next two years in line with the charity's strategic objectives and outcome for the long-term benefit of XLH patients.
Amount of reserves held	Para 1.22	£105,990
Reasons for holding zero reserves	Para 1.22	not applicable
Details of fund materially in deficit	Para 1.24	The charity is not in deficit.
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	The trustees have reviewed the charity's financial position and it considers that it remains a going concern and fully able to continue to deliver on its long-term objectives.

## Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	The organisation is governed by a trust deed dated 18 November 2017.
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	The organisation is an unincorporated charity.

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	Trustee selection is in accordance with the charity's governing document.  The policy and operating decisions of the charity rest with the trustees' who meet regularly to monitor the activities of the charity.
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## Reference and Administrative details

Charity name	XLH UK
Other name the charity uses	
Registered charity number	1182964
Charity's principal address	21 Providence Street  Greenhithe  Kent  DA9 9AA

## 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	Oliver Gardiner	n/a	18.11.2017 - present	
2	Amy Lee	n/a	18.11.2017 - present	
3	Nick Papé	n/a	18:11:2017 - present	
4	Sally Hatton	n/a	29.11.2020 - present	
5	Anne Papé	n/a	29:11:2020 - present	
6	Sarah Mitson	n/a	30:09:2021 - present	
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Corporate trustees – names of the directors at the date the report was approved

<b>Director name</b>		
<b>n/a</b>		

Name of trustees holding title to property belonging to the charity

<b>Trustee name</b>	<b>Dates acted if not for whole year</b>	
<b>n/a</b>		

**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	n/a

falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	n/a

## Exemptions from disclosure

Reason for non-disclosure of key personnel details

n/a
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## Other optional information

n/a
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## Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

	<b>Signature(s)</b>		<i>Oliver Gardiner</i>
	<b>Full name(s)</b>	Oliver Gardiner	
	<b>Position (eg Secretary, Chair, etc)</b>	Chair	
	<b>Date</b>	17/10/2021	

**XLH UK - Accounts for the year ended 31/01/2021****Income & Expenditure Account**

	£ 2020/21	£ 2019/20
Income		
Grants - XLH UK	1,863.38	40,235.00
Grants - XLH Alliance	64,864.00	0.00
Other	0.00	1.01
Total Income	<u>66,727.38</u>	<u>40,236.01</u>
Expenses		
Administration Expenses - XLH UK	310.85	251.71
Travel Expenses - XLH UK	0.00	112.10
Administration Expenses - XLH Alliance	267.52	31.31
Total Expenses	<u>578.37</u>	<u>395.12</u>
Surplus of Income over Expenditure	<u>66,149.01</u>	<u>39,840.89</u>

**Statement of Assets and Liabilities**

	£ 2020/21	£ 2019/20
XLH UK Funds - Bank Accounts	42,078.77	40,236.01
XLH UK Funds - Creditors	<u>(704.04)</u>	<u>(363.81)</u>

Net XLH UK		<b>41,374.73</b>	39,872.20
XLH Alliance Funds - Bank Accounts		<b>64,864.00</b>	0.00
XLH Alliance Funds - Creditors		<b>(248.83)</b>	<b>(31.31)</b>
Net XLH Alliance		<b>64,615.17</b>	<b>(31.31)</b>
<b>Net Assets</b>		<b><u>105,989.90</u></b>	<b><u>39,840.89</u></b>
Accumulated Surpluses Brought forward	39,840.89		0.00
Surplus in current year	66,149.01		<b>39,840.89</b>
<b>Accumulated Surpluses Carried Forward</b>		<b><u>105,989.90</u></b>	<b>39,840.89</b>



Section A

Independent Examiner's Report

Report to the trustees/  
members of

Charity Name  
XLH UK

On accounts for the year  
ended

31 JANUARY 2021

Charity no  
(if any)

1182964

Set out on pages

1

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/01/2021.

Responsibilities and  
basis of report

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

I report in respect of my examination of the Trust'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 material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- 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 accounts to be reached.

Signed:

*K Webb*

Date:

6/1/2021

Name:

KIM WEBB

Relevant professional  
qualification(s) or body  
(if any):

Address:

20 STAPLOE, ST NEOTS, CAMBRIDGESHIRE, PE19 5JA


**Section B**

**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

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