

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

Trustees

Oliver Gardiner

Sally Hatton

Shannon Sharp

Appointed 30th June 2022

Anne Papé

Resignation 14th December 2022

Charity number: 1182964

Principal Address:

21 Providence Street

Greenhithe

Wallingford

DA9 9AA

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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 30th November 2023 and signed on its behalf by:



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

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: 30th 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 £
Income					
Income and from:					
Donations and legacies	2	21,061	61,080	82,141	1,587
Total Income		21,061	61,080	82,141	1,587
Expenditure					
Charitable activities	3	5,215	61,080	66,295	1,182
Total Expenditure		5,215	61,080	66,295	1,182
Net Income/ (Expenditure)		15,846	-	15,846	405
Net movement in funds		15,846	-	15,846	405
Reconciliation of funds:					
Total funds brought forward	6-7	65,152	-	65,152	64,747
Total funds carried forward	6-7	80,998	-	80,998	65,152

International XKH Alliance
Balance Sheet at 31 January 2023

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

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

Signed on behalf of the board of Trustees by

Oliver Gardiner

Chair of Trustees

Oliver Gardiner

30/11/2023

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 1Accounting 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 29th 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 31st 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

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
Total	21,061	61,080	82,141	1,587

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
Total	5,215	61,080	66,295	1,182

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
Total	400

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
Total	26

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
Total	25,047	1,238

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)	-	80,998
Total	65,152	21,061	(5,215)	-	80,998

Last Year

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

International XKH Alliance

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

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 st 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.