



CHARITY COMMISSION
FOR ENGLAND AND WALES

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.		XLH UK 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

		<p>involved in the decision making that ultimately recommends new therapy for use with children with XLH in Scotland.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>International XLH Alliance</p>
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		<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		<p>XLH UK policy on working with pharmaceutical and medical device companies:</p> <p>https://xlhuk.org/xlh-uk-policy-on-working-with-pharmaceutical-and-medical-device-companies/</p>

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	<p>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.</p> <p>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.</p>
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

Director name		
n/a		

Name of trustees holding title to property belonging to the charity

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

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

Other optional information

n/a

Declarations

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

Signed on behalf of the charity's trustees

	Signature(s)		Oliver Gardiner
	Full name(s)	Oliver Gardiner	
	Position (eg Secretary, Chair, etc)	Chair	
	Date	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		41,374.73	39,872.20
XLH Alliance Funds - Bank Accounts		64,864.00	0.00
XLH Alliance Funds - Creditors		(248.83)	<u>(31.31)</u>
Net XLH Alliance		64,615.17	<u>(31.31)</u>
Net Assets		<u>105,989.90</u>	<u>39,840.89</u>

Accumulated Surpluses Brought forward	39,840.89		0.00
Surplus in current year	66,149.01		<u>39,840.89</u>
Accumulated Surpluses Carried Forward		<u>105,989.90</u>	<u>39,840.89</u>



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

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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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