

SOFT BONES UK FOUNDATION

England & Wales · Charity number 1181117

Details

Status Registered

Legal form CIO

Registered 2018-12-11

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

Contact

Address 37 Kelvin Grove
Fareham
Hampshire
PO16 8LQ

Phone 07525438841

Email info@softbonesuk.co.uk

Website www.softbonesuk.co.uk

Activities

Objects: THE RELIEF OF SICKNESS AND THE PRESERVATION AND PROTECTION OF GOOD HEALTH OF PERSONS SUFFERING FROM WITH HYPOPHOSPHATASIA (HPP), THEIR FAMILIES AND CARERS AND, FOR THE BENEFIT OF THE PUBLIC, PARTICULARLY BUT NOT EXCLUSIVELY BY:A) PROMOTING GREATER UNDERSTANDING OF THE CAUSES, SYMPTOMS AND TREATMENT OF HPPB) RAISING PUBLIC AWARENESS OF THE SYMPTOMS, NEEDS AND RELATED MEDICAL CONDITIONS OF THOSE LIVING WITH HPP C) ASSISTING PEOPLE WITH HPP, THEIR RELATIVES AND CARERS TO GET IN CONTACT WITH EACH OTHER AND TO EXCHANGE INFORMATION AND EXPERIENCES.

Activities: The objectives of Softbones UK is to promote greater understanding of the causes, symptoms and treatment of HPP; raise public awareness of the symptoms, needs and related medical conditions of those living with HPP and assist people with HPP, their relatives and carers to get in contact with each other and to exchange information and experiences.

Classification

- **How:** Makes Grants To Individuals, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Hampshire

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05		-	-	-
2024-04-05	£1,235	£1,184	-	-
2023-04-05	£110	£240	-	-
2022-04-05	£1,105	£3,641	-	-
2021-04-05	£2,708	£774	-	-
2020-04-05	£8,400	£7,062	-	-

Trustees

Name	Role	Appointed
ALEXANDRA INGLIS OCKENDEN	Chair	2018-11-16
EMMY SKINNER		2018-11-17
LEE CORSTORPHIN		2018-11-25
MERYL IONA CHAMBERS		2018-09-23
SUSAN MARGARET HOMAN		2018-11-21

SOFT BONES UK FOUNDATION

England & Wales - Charity number 1181117

Accounts



**Trustees of
Soft Bones UK Foundation
Registered Charity
No: 1181117**

Statement of Accounts

for the year

1st April 2023 – 31st March 2024

**Prepared by A Ockenden
Trustee
Soft Bones UK Foundation**

**Trustees of Soft Bones UK Foundation
Year ended 31st March 2024**

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**Trustees of Soft Bones UK Foundation
Year ended 31st March 2024**

CHARITY PARTICULARS

Charity registration no:

1181117

Trustees

**Meryl Chambers
Lee Corstorphin
Susan Homan
Sandra Ockenden
Rina Skinner**

**Chair & Co-ordinator
Finance/Fundraising
Treasurer
Technical Support
Communications**

**Correspondence address
(Chair)**

**37 Kelvin Grove
Portchester
Fareham
Hampshire
PO16 8LQ**

Principal Bankers

**Lloyds Bank
Andover
BX1 1LT**

Trustees of Soft Bones UK Foundation
Year ended 31st March 2024

Trustees Annual Report

Constitution

Soft Bones UK Foundation is constituted by a conveyance document dated 16th September 2018 and is registered with the Charity Commission under Charity Number 1181117.

Organisation

The charity is administered by an elected board of Trustees who normally meet a minimum of three times a year. The names of serving trustees and the other charity particulars are listed above. New or co-opted members are appointed, inducted and given details of their responsibilities by the Trustees and very little continuous training is required.

Aims and Objectives

The charity aims are to promote greater understanding of the causes, symptoms and treatment of Hypophosphatasia (HPP); to raise public awareness of the symptoms, needs and related medical conditions of those living with HPP and to assist people, their relatives and carers to get in contact with each other and to exchange information and experiences.

Achievements (April 2023 – March 2024)

Meryl Chambers, Chair, attended the OIFE Topical Meeting 2023: Balancing Life with OI: Pain and its impact in Stockholm in June 2023. This included discussions on pain in OI and other rare bone conditions, commonalities and differences and how we can work together. Meryl Chambers presented at the conference to inform the audience of Hypophosphatasia, the symptoms and HPP testimonials. Meryl Chambers also took part in a panel debate on pain across rare bone disease groups as a representative from the HPP community.

Collaboration

We continue to work closely with Metabolic Support UK and alongside Softbones USA.

Thanks to our Supporters

We would like to thank everyone who fundraised for Softbones UK. In particular, charity quiz night run by Simon Cornwell and the Broad Oak Social Club.

Donations and Grants

£1,235

Alexandra Ockenden
Trustee of Soft Bones Foundation UK

A Ockenden

Dated

12/12/2024

Trustees of Soft Bones UK Foundation
Year ended 31st March 2024

Treasurer's Report

In order to fulfil our duties under the Charities Act 1993, I have compiled financial spreadsheets for the charity recording all expenditure and income, including petty cash payments, for this financial year ended 31st March 2024.

All these payments have been checked against receipts in the bank account and recorded as income or expenditure to give a true and fair view under the Charities Act 1993.

S Homan

Susan Homan
Treasurer

11/12/2024

Dated

Trustees of Soft Bones UK Foundation - Year ending 31st March 2024

Receipts and Payments Account

Receipts	2023		2024
	to nearest	Unrestricted	
		£	£
Donations	0		-
Fundraising/events	-		1,235
Grant	-		-
Total Receipts	0		1,235

Payments	2023		2024
		£	£
Sundries	40		-
Google Suite	41		14
Website	122		43
OIFE Conference, Stockholm	712		-
Membership	158		-
Raffle Donation (Quiz)	-		54
Total Payments	1,073		111
Cash and bank balance at year end	3,257		
Asset purchases	-		-
Receipts	-		1,235
Expenditure	1,073		111

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England & Wales - Charity number 1181117

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Statement of Accounts

for the year

1st April 2022 – 31st March 2023

**Prepared by A Ockenden
Trustee
Soft Bones UK Foundation**

**Trustees of Soft Bones UK Foundation
Year ended 31st March 2023**

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**Trustees of Soft Bones UK Foundation
Year ended 31st March 2023**

CHARITY PARTICULARS

Charity registration no: 1181117

Trustees	Meryl Chambers Lee Corstorphin Susan Homan Sandra Ockenden Rina Skinner	Chair & Co-ordinator Finance/Fundraising Treasurer Technical Support Communications
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Correspondence address (Chair)	37 Kelvin Grove Portchester Fareham Hampshire PO16 8LQ
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Principal Bankers	Lloyds Bank Andover BX1 1LT
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Trustees of Soft Bones UK Foundation
Year ended 31st March 2023

Trustees Annual Report

Constitution

Soft Bones UK Foundation is constituted by a conveyance document dated 16th September 2018 and is registered with the Charity Commission under Charity Number 1181117.

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Aims and Objectives

The charity aims are to promote greater understanding of the causes, symptoms and treatment of Hypophosphatasia (HPP); to raise public awareness of the symptoms, needs and related medical conditions of those living with HPP and to assist people, their relatives and carers to get in contact with each other and to exchange information and experiences.

Achievements (April 2022 – March 2023)

The HPP information packs have been printed and delivered to all children's hospitals in the UK. We continue to increase our social media footprint to make information about HPP more accessible.

Collaboration

We continue to work closely with Metabolic Support UK and alongside Softbones USA.

Thanks to our Supporters

We would like to thank everyone who fundraised for Softbones UK.

Donations and Grants

2110

Alexandra Ockenden
Trustee of Soft Bones Foundation UK

.....
A. J. Ockenden

Dated

.....
26/03/24

Trustees of Soft Bones UK Foundation
Year ended 31st March 2023

Treasurer's Report

In order to fulfil our duties under the Charities Act 1993, I have compiled financial spreadsheets for the charity recording all expenditure and income, including petty cash payments, for this financial year ended 31st March 2023.

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.....
S. Homan
Susan Homan
Treasurer

.....
26/03/24
Dated

Trustees of Soft Bones UK Foundation - Year ending 31st March 2023

Receipts and Payments Account

Receipts	2022	2023
	Unrestricted to nearest £	£
Donations	110	-
Fundraising/events	-	-
Grant	-	-
Total Receipts	110	-

Payments	2022	2023
	£	£
Sundries	20	-
Google Suite	41	14
Website	122	43
Special Project - HPP	-	-
Information Pack (Production)	-	-
Donation	-	-
Travel Expenses	-	-

Total Payments	183	57
Cash and bank balance at year end	3,435	
Asset purchases	-	-
Receipts	110	-
Expenditure	183	57

SOFT BONES UK FOUNDATION

England & Wales - Charity number 1181117

Accounts



**Trustees of
Soft Bones UK Foundation
Registered Charity
No: 1181117**

Statement of Accounts

for the year

5th April 2021 – 31st March 2022

**Prepared by A Ockenden
Trustee
Soft Bones UK Foundation**

**Trustees of Soft Bones UK Foundation
Year ended 31st March 2022**

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Year ended 31st March 2022**

CHARITY PARTICULARS

Charity registration no:

1181117

Trustees

**Meryl Chambers
Lee Corstorphin
Susan Homan
Sandra Ockenden
Rina Skinner**

**Chair & Co-ordinator
Finance/Fundraising
Treasurer
Technical Support
Communications**

**Correspondence address
(Chair)**

**5 Southfields
Portchester
Fareham
Hampshire
PO16 9FG**

Principal Bankers

**Lloyds Bank
Andover
BX1 1LT**

Trustees of Soft Bones UK Foundation
Year ended 31st March 2022

Trustees Annual Report

Constitution

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Aims and Objectives

The charity aims are to promote greater understanding of the causes, symptoms and treatment of Hypophosphatasia (HPP); to raise public awareness of the symptoms, needs and related medical conditions of those living with HPP and to assist people, their relatives and carers to get in contact with each other and to exchange information and experiences.

Achievements (April 2021 – March 2022)

The HPP information packs have been printed and are now in the process of being delivered to all children's hospitals in the UK. We continue to increase our social media footprint to make information about HPP more accessible.

Collaboration

We participated in the Rare Thinking Conference in November 2021 and continue to work closely with Metabolic Support UK and alongside Softbones USA.

Thanks to our Supporters

We would like to thank everyone who fundraised for Softbones UK.

Donations and Grants
£1,105

Alexandra Ockenden
Trustee of Soft Bones Foundation UK

A. J. Ockenden

Dated

12/12/2022

Trustees of Soft Bones UK Foundation
Year ended 31st March 2022

Treasurer's Report

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S Homan

.....

Susan Homan
Treasurer

11/12/2022

.....

Dated

Trustees of Soft Bones UK Foundation - Year ending 4th April 2022

Receipts and Payments Account

Receipts	2021		2022
	to nearest	Unrestricted £	£
Donations	-	-	-
Fundraising/events	662		443
Grant	-		-
Total Receipts		662	443

Payments	2021		2022
		£	£
Sundries		30	-
Google Suite		41	14
Website		106	66
Special Project - HPP			
Information Pack (Production)		1,217	-
Donation		1,695	-
Travel Expenses		-	478
Total Payments		3,089	558

Cash and bank balance at year end 3,565

Asset purchases -

Receipts	662	443
Expenditure	3,089	558

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England & Wales - Charity number 1181117

Accounts



**Trustees of
Soft Bones UK Foundation
Registered Charity
No: 1181117**

Statement of Accounts

for the year

7th April 2020 – 31st March 2021

**Prepared by A Ockenden
Trustee
Soft Bones UK Foundation**

**Trustees of Soft Bones UK Foundation
Year ended 31st March 2021**

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**Trustees of Soft Bones UK Foundation
Year ended 31st March 2021**

CHARITY PARTICULARS

Charity registration no: 1181117

Trustees

**Meryl Chambers
Lee Corstorphin
Susan Homan
Sandra Ockenden
Rina Skinner**

**Chair & Co-ordinator
Finance/Fundraising
Treasurer
Technical Support
Communications**

**Correspondence address
(Chair)**

**5 Southfields
Portchester
Fareham
Hampshire
PO16 9FG**

Principal Bankers

**Lloyds Bank
Andover
BX1 1LT**

Trustees of Soft Bones UK Foundation
Year ended 31st March 2021

Trustees Annual Report

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Achievements (April 2020 – March 2021)

The coronavirus pandemic meant that this was a year unlike any other. We continued to secure funding from tremendous funders but had to postpone various events. Assisted by Metabolic Support UK, we did our utmost to respond to challenges in communication flow to a worried HPP community. The focus of our work changed and we switched our efforts into the design and production of an HPP Information Pack, which will be distributed to all children's hospitals in the UK. We continued to increase our social media footprint to make information about HPP more accessible.

We have also been working alongside Metabolic Support U.K. and Dr Katie Moss on an adult HPP leaflet.

We worked closely with Metabolic Support UK in an important survey about the Managed Access Agreement and the return to clinics for healthcare assessments when shielding ends.

Collaboration

Virtual conferences and webinar events were arranged during the pandemic. Some of those represented by Softbones UK included; Climb Hq (Facing Coronavirus Together); BBS Q&A session on the Relaxation of Restrictions and the Metabolic Support UK virtual conference, which had a breakout session for Hypophosphatasia. We continue to work alongside Softbones USA.

Thanks to Fund-Raisers



**Fundraisers – Leon Ockenden –
April 2020 - £534.14**

**Engie Christmas 2019 Fundraiser
£741.50**



**A fantastic £1,000 donation
From Edale, Whiteley, Fareham**

**Fundraiser Simon Donhou completed the
Boxhill Sportive Cycle in September 2020
and raised a fantastic £350**

**Donations and Grants
£2,710**

Alexandra Ockenden
Trustee of Soft Bones Foundation UK

A. Ockenden

Dated

21/10/21

**Trustees of Soft Bones UK Foundation
Year ended 31 March 2021**

Treasurer's Report

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S Homan

Susan Homan
Treasurer

21/10/21

Dated

Trustees of Soft Bones UK Foundation - Year ending 31st March 2021

Receipts and Payments Account

Receipts	2020		2021
	to nearest	Unrestricted	
	£	£	£
Donations	-	-	-
Fundraising/events	1708		1000
Grant	-	-	-
Total Receipts	1708		1000

Payments	2020		2021
	£	£	£
Sundries	-	-	-
Google Suite	38		14
Website	111		37
Special Project - HPP			
Information Pack (Layout & Design)	574		

Total Payments	723	51
Cash and bank balance at year end	6121	
Asset purchases	-	-
Receipts	1708	1000
Expenditure	723	52