

ACRODYSOSTOSIS SUPPORT & RESEARCH

England & Wales · Charity number 1182818

Details

Status Registered

Legal form CIO

Registered 2019-04-05

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

Contact

Address Bath House
Cudworth Lane
Newdigate
Dorking
Dorking
Surrey

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Email info@acrodysostosis.com

Website www.acrodysostosis.com

Activities

Objects: THE OBJECTS OF THE CIO ARE TO RELIEVE THE NEEDS OF THOSE AFFECTED BY ACRODYSOSTOSIS DISEASE, THEIR FAMILIES, FRIENDS AND CARERS BY:-(1) PROMOTING GREATER UNDERSTANDING OF THE CAUSES, SYMPTOMS AND TREATMENT OF ACRODYSOSTOSIS DISEASE IN ALL ITS FORMS INCLUDING BY THE PROMOTION OF RESEARCH AND SHARING AND DISSEMINATING OF THE RESULTS OF SUCH RESEARCH FOR THE BENEFIT OF THE GENERAL PUBLIC;(2) RAISING PUBLIC AWARENESS OF THE SYMPTOMS, NEEDS AND RELATED MEDICAL CONDITIONS OF THOSE LIVING WITH ACRODYSOSTOSIS DISEASE.

Activities: The activities of the CIO are to relieve the needs of those affected by Acrodysostosis by promoting greater understanding of the causes, symptoms and treatment of Acrodysostosis in all its forms including by the promotion of research and sharing and disseminating of results of such research for the benefit of the general public; raising public awareness of the symptoms

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training
- **Who:** People With Disabilities, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£2,036	£1,937	-	-
2023-12-31	£5,076	£3,925	-	-
2022-12-31	£22,836	£23,284	-	-
2021-12-31	£12,391	£63,318	-	-
2020-12-31	£89,873	£3,849	-	-

Trustees

Name	Role	Appointed
Nina Samantha Knight	Chair	2019-10-01
Jan Sara Hine		2019-10-01
Sarah Louise Denney		2019-10-01

ACRODYSOSTOSIS SUPPORT & RESEARCH

England & Wales - Charity number 1182818

Accounts

Charity number: 1182818

Company number: CE017079

(England and Wales)

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2024

ACRODYSOSTOSIS SUPPORT & RESEARCH

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For the year ended 31 December 2024

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ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees

For the year ended 31 December 2024

The Trustees, who are also directors for the purposes of company law, have pleasure in presenting their report and the financial statements for the charitable company for the year ended 31 December 2024. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2015).

Chair's report

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and the accounts in accordance with Charities Act 2011 and United Kingdom Generally Accepted Accounting Practice.

The Charities Act 2011 requires the Trustees to prepare accounts for each financial year which give a true and fair view of its financial activities during the year and of its financial position at the end of the year. In presenting those accounts, they are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP FRS 102;
- make judgements and estimates that are reasonable and prudent;
- follow applicable UK accounting standards and the Charities SORP FRS 102, disclosing and explaining any departures in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to do so.

The Trustees are responsible for maintaining 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 accounts comply with the Charities Act 2011 and with the requirements of the Statement of Recommended Practice Accounting and Reporting by Charities: statement of recommended practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) - Charities SORP FRS102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102). They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities besides the above responsibilities.

This report was approved by the trustees on 24th October 2025

OBJECTIVES AND ACTIVITIES

Charitable objectives:

To relieve the needs of those affected by Acrodysostosis by promoting greater understanding of the causes, symptoms, and treatment of Acrodysostosis in all its forms including:

- promoting research and sharing and disseminating of results of such research for the benefit of the general public; and
- raising public awareness of the symptoms, needs and related medical conditions of those living with Acrodysostosis.

Charitable activities:

The Trustees ensure that sufficient attention is paid to fundraising activities, monitoring grant funding opportunities and manage the charity's assets to ensure its sustainability and ability to carry out its charitable objectives. The charity relies heavily on its volunteers as it has no paid members of staff.

Objectives and aims

In exercising their duty, the Trustees confirm that they have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

The charity's objectives are to offer support and information to families affected by Acrodysostosis. Acrodysostosis Support & Research liaises closely with researchers at UCL Great Ormond St Hospital (UCL GOSH) with regards to the ongoing pioneering research into Acrodysostosis. Additionally, the charity is actively engaged in collaborative efforts with researchers from the University of Manchester, University of Glasgow and Keele University and also works constructively and in partnership with other agencies and organisations to continually improve support for families affected by Acrodysostosis - to change lives and make a difference to those living with the condition.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued
For the year ended 31 December 2024

ACHIEVEMENTS AND PERFORMANCE

Key activities and achievements throughout the year include:

Peer Support:

- One of the main aims of the charity is to bring together families and the Acrodysostosis community to share experiences and provide peer support through the Acrodysostosis network. The charity provides this support to their families via their ambassadors who are always available to listen and provide emotional and practical help to their Acrodysostosis Families.

- Acrodysostosis have continued to provide a range of information offering guidance and support for Acrodysostosis families.

General Support:

- Acrodysostosis families have found comfort from hearing and sharing experiences via the Acrodysostosis private Support Facebook group as well as various zoom meetings which any of the Acrodysostosis community could attend and get the opportunity to meet virtually.

- Acrodysostosis Support & Research have continued to provide a range of information offering guidance and support for Acrodysostosis families including:

Medical Advisory Board (MAB)

The MAB was formed to guide the trustees in scientific matters, including research efforts and direction, and consists of renowned experts in the field. The MAB continues to meet regularly to facilitate the expanding body of knowledge around Acrodysostosis so families can be better supported - the trustees are very grateful to the MAB members for their dedication and commitment to helping Acrodysostosis families. The MAB along with Trustees and Ambassadors are continuing to take the lead in identifying research opportunities. And through a roundtable meeting which was sponsored by Costello medical the charity was able to bring together all the researchers, MAB, Trustee and Ambassadors to discuss the future landscape for research into Acrodysostosis with the aim of finding treatments.

Communications:

- Communications with those within the Acrodysostosis community and the general public through the Acrodysostosis website, and via social media.

- On Facebook a public page for the general public is used as their primary form of outbound communication. The charity also has a closed support group for families affected by the condition.

- Acrodysostosis is also active on LinkedIn, Twitter and Instagram pages.

Research:

- In 2024 - GOSH Charity's "Funded National Call Projects"; Dr Melissa Bowerman, Keele University was awarded: £249,631.08 for GOSH Charity National Call 202324 (Research Project Grants) Project title: "Assessing novel mutant-selective PDE4D PROTACs to restore molecular and functional pathologies in a mouse model of ACRDYS 2."

- Acrodysostosis Support & Research is actively collaborating with its Medical Advisory Board (MAB) and the Acrodysostosis Community to introduce a global Acrodysostosis patient registry. Simultaneously, the charity has been diligently gathering data through the first-ever community survey in Acrodysostosis.

- With the support of Acrodysostosis Support and Research Dr Melissa Bowerman and Prof George Baille were awarded a grant of £1,036,199.30 for 3 years from the MRC here is summary: They have recently generated a new mouse model for ACRDYS 2 that presents similar features to the human condition such as a small size, reduced weight and abnormal brain function. They propose to firstly further characterise this novel mouse model, whereby the animals will be observed to record the range of symptoms that occur in ACRDYS 2 patients. They will also evaluate the effect of PDE4D blocking drugs (existing and newly developed) on the symptoms and other regulatory molecules in this mouse model. This novel mouse model will be an invaluable tool for scientists, doctors and patients to help better understand the different aspects of the disease and importantly, develop new treatments that can prevent and/or slow down the symptoms in ACRDYS 2 and other conditions where activity of PDE4D is abnormally increased.

- In 2024, with the invaluable support of Acrodysostosis Support & Research, Professor Sue Kimber continues her 5-year project awarded by the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR). This represents a significant milestone in the ongoing efforts to advance the understanding of rare conditions including Acrodysostosis. Here is a summary: "In patients with Acrodysostosis, genetic mutations disrupt the response of growth plate cartilage to hormones. A research team has developed a method to cultivate growth plate-like cartilage from stem cells and manipulate genes. Their project aims to replicate these genetic mutations in stem cells, generating defective cartilage for comparison with normal cartilage. By analysing the

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued For the year ended 31 December 2024

RNA molecules responsible for protein coding, they hope to pinpoint the molecular-level issues in cartilage formation. This research is expected to identify key molecules causing the disease, potentially paving the way for future drug treatments."

Raising Awareness

- Chosen as Charity Partner in PM Society "Creativity for Good" 2024

- In June 2024, the PM Society announced that Acrodysostosis Support & Research would be their charity partner for the Creativity for Good 2024/25 initiative. The role involves agencies pitching campaign ideas (pro bono) to help raise awareness or meet the charity's objectives. At year-end, the PM Society reflected on this partnership, noting that the number of participating agencies was significantly higher than in previous years, and that it would help them with awareness in the medical community (i.e. enabling clinicians to better recognise the disease).

- In March 2024 - The charity attended the Advanced Therapies Congress which is Europe's largest cell and gene therapy conference and exhibition in London. It's attended by 2,000 delegates, 100 exhibitors, 200 innovative young start-ups and 300 speakers from across the entire value chain of cell and gene therapy development; including forward-thinking pharma companies, researchers, clinicians, academics, HTAs, payers and regulators.

- In September 2024 - Nina Knight the chair of the charity renews as an ePAG@ERN-ITHACA (patient advisory board member at the European reference network for rare malformation syndromes and rare intellectual and neurodevelopmental disorders). The role of ePAG is to represent the voice and interests of their patient community and act as the bridge between this community and the ERN. ePAG have an official permanent mandate to represent ePAG member organisations. They liaise with these organisations to ensure true and equitable representation of the patient voice by participating in the Board and sub-clinical committees of their respective ERN.

- In December 2024 - The charity attended the annual board meeting for ITHACA ePAGS in Romania.

Fundraising:

- The charity received more than £2000 in donations from the Acrodysostosis community.

- Furthermore, in addition to the financial contributions from parents, patients, and friends of the charity, a substantial number of volunteer hours have been dedicated to Acrodysostosis Support & Research. These individuals have passionately supported families and remain steadfast in their commitment to advancing the scientific understanding of this disease. Their collective efforts are focused on expediting the development of viable treatments and, ideally, a cure in the future.

FINANCIAL REVIEW

Financial review and reserves policy

The charity Trustees continually monitor cash reserves to ensure its financial stability.

Acrodysostosis Support & Research is committed to building a reserves policy to ensure there is enough funding to cover one year's operating costs.

The charity has no outstanding financial obligations nor outstanding debts. The charity's principal source of funds comes from the general public, either through donations or at one-off fundraising events.

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	ACRODYSOSTOSIS SUPPORT & RESEARCH
Charity registration number	1182818
Company registration number	CE017079
Principal address	Bath House, Cudworth Lane Newdigate Dorking Surrey SE15 5AF

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued
For the year ended 31 December 2024

Trustees

The trustees and officers serving during the year and since the year end were as follows:

Jan Sara Hine
Sarah Louise Denney
Nina Samantha Knight

Independent examiners

Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

Approved by the Board of Trustees and signed on its behalf by



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24 October 2025

Nina Samantha Knight

ACRODYSOSTOSIS SUPPORT & RESEARCH
Independent Examiners Report to the Trustees
For the year ended 31 December 2024

I report to the trustees on my examination of the accounts of the charitable company for the year ended 31 December 2024.

Responsibilities and basis of report

As the charity Trustees, who are also directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.



Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

24 October 2025

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Activities (including Income and Expenditure Account)
For the year ended 31 December 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 £	2023 £
Income and endowments from:					
Donations and legacies	2	2,036	-	2,036	5,076
Total		2,036	-	2,036	5,076
Expenditure on:					
Raising funds	3	(271)	-	(271)	(255)
Charitable activities		(1,666)	-	(1,666)	(3,670)
Total		(1,937)	-	(1,937)	(3,925)
Net income/expenditure		99	-	99	1,151
Reconciliation of funds					
Total funds brought forward		32,383	3,417	35,800	34,649
Total funds carried forward		32,482	3,417	35,899	35,800

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Position
As at 31 December 2024

	Notes	2024 £	2023 £
Current assets			
Debtors		482	431
Cash at bank and in hand		40,630	39,588
		41,112	40,019
Creditors: amounts falling due within one year	9	(5,213)	(4,219)
Net current assets		35,899	35,800
Total assets less current liabilities		35,899	35,800
Net assets		35,899	35,800
The funds of the charity			
Restricted income funds	10	3,417	3,417
Unrestricted income funds	10	32,482	32,383
Total funds		35,899	35,800

For the year ended 31 December 2024 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:



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Nina Samantha Knight
Trustee

24 October 2025

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements

For the year ended 31 December 2024

1. Accounting Policies

Basis of accounting

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015), Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the (2011 or 2006 Act).

ACRODYSOSTOSIS SUPPORT & RESEARCH meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

The financial statements are prepared in sterling, which is the functional currency of the entity.

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

Funds

Unrestricted funds are incoming resources receivable or generated for the furtherance of the objectives of the Charity without a specified purpose and are available as general funds. Resources expended which meet these criteria are charged to the funds, together with a fair allocation of staff and support costs. Restricted funds are used for the specific purposes laid down by the donor or sponsor. Resources expended which meet these criteria are charged to the funds.

Taxation

The Charity is exempt from taxation on its charitable activities, as it is a registered charity.

Debtors

Debtors are recognised at the settlement amount due after allowing for any discounts and as per the terms agreed. Prepayments are valued at the amounts prepaid for services and accrued income are valued at the amounts due per terms agreed and there is certainty of receipt.

Income and interest receivable

Income is recognised in the period when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably and is not deferred.

Income received in advance of the provision of a specified service is deferred until the criteria for income recognition are met.

Income comprises of funds received from donations as well as gift aid,

The value of services provided by volunteers has not been included.

Other accounting policies

Cash at bank and in hand:

Cash at bank and cash in hand includes bank balance kept in current and deposit accounts.

Creditors and provisions:

Creditors and provisions 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 and provision are normally recognised at their settlement amount after allowing for any discounts.

Financial instruments:

The charity only has financial assets and financial liabilities of a kind that qualifies as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their amortised costs.

Critical accounting estimates and judgements:

There are no significant areas of judgement or key sources of estimation uncertainty arising from the preparation of accounts.

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2024

2. Income from donations and legacies

	2024	2023
	£	£
Unrestricted funds		
Donations received	2,036	321
Gifts in kind	-	4,755
	2,036	5,076
	2,036	5,076

3. Expenditure on generating donations and legacies

	2024	2023
	£	£
Unrestricted funds		
Support costs	271	255
	271	255
	271	255

4. Analysis of support costs

	2024	2023
	£	£
Governance costs		
Accountancy fees	720	963
Subscriptions	946	2,707
Insurance	271	255
	1,937	3,925

5. Net income/(expenditure) for the year

This is stated after charging/(crediting):

	2024	2023
	£	£
Accountancy fees	720	963
	720	963

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2024

6. Staff costs and emoluments

	2024	2023
General staff	0	0
	0	0
	0	0

7. Trustee remuneration and related party transactions

There are no disclosable reimbursements to trustees in this financial period.

All amounts reimbursed in the year to trustees related to costs for fulfilling their duties as trustees as well as the reimbursement of costs which relate to the furtherance of the charity's objectives.

8. Comparative for the Statement of Financial Activities

The comparative year values on the Statement of Financial Activities are for unrestricted funds.

9. Creditors: amounts falling due within one year

	2024	2023
	£	£
Other creditors	4,493	3,499
Accruals and deferred income	720	720
	5,213	4,219
	5,213	4,219

Included in other creditors is an amount due to the trustees for expense claims. The amount should be repaid within 12 months of the year end.

10. Movement in funds

Unrestricted Funds

	Balance at 01/01/2024	Incoming resources	Outgoing resources	Balance at 31/12/2024
	£	£	£	£
<i>General</i>				
General	32,383	2,036	(1,937)	32,482
	32,383	2,036	(1,937)	32,482
	32,383	2,036	(1,937)	32,482

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements Continued

For the year ended 31 December 2024

Unrestricted Funds - Previous year

	Balance at 01/01/2023	Incoming resources	Outgoing resources	Balance at 31/12/2023
	£	£	£	£
<i>General</i>				
General	31,232	5,076	(3,925)	32,383
	<u>31,232</u>	<u>5,076</u>	<u>(3,925)</u>	<u>32,383</u>

Purpose of unrestricted Funds

General

To fulfil the principal objectives of the charity.

Restricted Funds

	Balance at 01/01/2024	Balance at 31/12/2024
	£	£
Family Day	3,417	3,417
	<u>3,417</u>	<u>3,417</u>

Restricted Funds - Previous year

	Balance at 01/01/2023	Balance at 31/12/2023
	£	£
Family Day	3,417	3,417
	<u>3,417</u>	<u>3,417</u>

Purpose of restricted funds

Family Day

Delivering a family day for attendees as prescribed by the donors.

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2024

11. Analysis of net assets between funds

	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
General	32,482	32,482
Restricted funds		
Family Day	3,417	3,417
	35,899	35,899
 Previous year		
	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
General	32,383	32,383
Restricted funds		
Family Day	3,417	3,417
	35,800	35,800

ACRODYSOSTOSIS SUPPORT & RESEARCH
Detailed Statement of Financial Activities
For the year ended 31 December 2024

	2024	2023
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	2,036	321
Gifts in kind	-	4,755
	2,036	5,076
Total incoming resources	2,036	5,076
SUPPORT COSTS		
Governance costs		
Governance costs	(271)	(255)
Governance costs (Donation collections)	(1,666)	(3,670)
	(1,937)	(3,925)
Total resources expended	(1,937)	(3,925)
Net Income	99	1,151

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Document Signers

Signer 1

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Document Signers

Signer 1

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More Information

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ACRODYSOSTOSIS SUPPORT & RESEARCH

England & Wales - Charity number 1182818

Accounts

Charity number: 1182818
Company number: CE017079
(England and Wales)

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2023

ACRODYSOSTOSIS SUPPORT & RESEARCH

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ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees

For the year ended 31 December 2023

The Trustees, who are also directors for the purposes of company law, have pleasure in presenting their report and the financial statements for the charitable company for the year ended 31 December 2023. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2015).

Chair's report

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and the accounts in accordance with Charities Act 2011 and United Kingdom Generally Accepted Accounting Practice.

The Charities Act 2011 requires the Trustees to prepare accounts for each financial year which give a true and fair view of its financial activities during the year and of its financial position at the end of the year. In presenting those accounts, they are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP FRS 102;
- make judgements and estimates that are reasonable and prudent;
- follow applicable UK accounting standards and the Charities SORP FRS 102, disclosing and explaining any departures in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to do so.

The Trustees are responsible for maintaining 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 accounts comply with the Charities Act 2011 and with the requirements of the Statement of Recommended Practice Accounting and Reporting by Charities: statement of recommended practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) - Charities SORP FRS102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102). They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities besides the above responsibilities.

This report was approved by the trustees on 17th October 2024

OBJECTIVES AND ACTIVITIES

Charitable objectives:

To relieve the needs of those affected by Acrodysostosis by promoting greater understanding of the causes, symptoms, and treatment of Acrodysostosis in all its forms including:

- promoting research and sharing and disseminating of results of such research for the benefit of the general public; and
- raising public awareness of the symptoms, needs and related medical conditions of those living with Acrodysostosis.

Charitable activities:

The Trustees ensure that sufficient attention is paid to fundraising activities, monitoring grant funding opportunities and manage the charity's assets to ensure its sustainability and ability to carry out its charitable objectives. The charity relies heavily on its volunteers as it has no paid members of staff.

Objectives and aims

In exercising their duty, the Trustees confirm that they have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

The charity's objectives are to offer support and information to families affected by Acrodysostosis. Acrodysostosis Support & Research liaises closely with researchers at UCL Great Ormond St Hospital (UCL GOSH) with regards to the ongoing pioneering research into Acrodysostosis. Additionally, the charity is actively engaged in collaborative efforts with researchers from the University of Manchester, University of Glasgow and Keele University and also works constructively and in partnership with other agencies and organisations to continually improve support for families affected by Acrodysostosis - to change lives and make a difference to those living with the condition.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued
For the year ended 31 December 2023

ACHIEVEMENTS AND PERFORMANCE

Key activities and achievements throughout the year include:

Peer Support

- One of the main aims of the charity is to bring together families and the Acrodysostosis community to share experiences and provide peer support through the Acrodysostosis network. The charity provides this support to their families via their ambassadors who are always available to listen and provide emotional and practical help to their Acrodysostosis Families.
- Acrodysostosis have continued to provide a range of information offering guidance and support for Acrodysostosis families.

General Support

Acrodysostosis families have found comfort from hearing and sharing experiences via the Acrodysostosis private Support Facebook group as well as various zoom meetings which any of the Acrodysostosis community could attend and get the opportunity to meet virtually.

Acrodysostosis Support & Research have continued to provide a range of information offering guidance and support for Acrodysostosis families including:

Medical Advisory Board (MAB):

The MAB was formed to guide the trustees in scientific matters, including research efforts and direction, and consists of renowned experts in the field. The MAB continues to meet regularly to facilitate the expanding body of knowledge around Acrodysostosis so families can be better supported - the trustees are very grateful to the MAB members for their dedication and commitment to helping Acrodysostosis families. The MAB along with Trustees and Ambassadors are continuing to take the lead in identifying research opportunities. And through a roundtable meeting which was sponsored by Costello medical the charity was able to bring together all the researchers, MAB, Trustee and Ambassadors to discuss the future landscape for research into Acrodysostosis with the aim of finding treatments.

Communications:

- Communications with those within the Acrodysostosis community and the general public through the Acrodysostosis website, and via social media.
- On Facebook a public page for the general public is used as their primary form of outbound communication. The charity also has a closed support group for families affected by the condition.
- Acrodysostosis is also active on LinkedIn, Twitter and Instagram pages.

Research:

- Acrodysostosis Support & Research is actively collaborating with its Medical Advisory Board (MAB) and the Acrodysostosis Community to introduce a global Acrodysostosis patient registry. Simultaneously, the charity has been diligently gathering data through the first-ever community survey in Acrodysostosis.
- In February 2023 the article "Growth patterns and outcomes of growth hormone therapy in patients with acrodysostosis" by Ertl, Diana-Alexandra was published online in Journal of Endocrinological Investigation. Along with Ertl, Diana-Alexandra, this was a collaboration between Acrodysostosis Support & Research and their community. The Chair and on one of the Ambassadors have been included as co-authors. This is part of the Springer Nature Content Sharing Initiative, here is the link to view the paper: <https://rdcu.be/c479M>
- With the support of Acrodysostosis Support and Research Dr Melissa Bowerman and Prof George Baille were awarded a grant of £1,036,199.30 for 3 years from the MRC here is summary: They have recently generated a new mouse model for ACRDYS 2 that presents similar features to the human condition such as a small size, reduced weight and abnormal brain function. They propose to firstly further characterise this novel mouse model, whereby the animals will be observed to record the range of symptoms that occur in ACRDYS 2 patients. They will also evaluate the effect of PDE4D blocking drugs (existing and newly developed) on the symptoms and other regulatory molecules in this mouse model. This novel mouse model will be an invaluable tool for scientists, doctors and patients to help better understand the different aspects of the disease and importantly, develop new treatments that can prevent and/or slow down the symptoms in ACRDYS 2 and other conditions where activity of PDE4D is abnormally increased.
- In 2023, with the invaluable support of Acrodysostosis Support & Research, Professor Sue Kimber continues her 5-year project awarded by the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR). This represents a significant milestone in the ongoing efforts to advance the understanding of rare conditions including Acrodysostosis. Here is a summary: In patients with Acrodysostosis, genetic mutations disrupt the response of growth plate cartilage to hormones. A research team has developed a method to cultivate growth plate-like cartilage from stem cells and manipulate genes. Their project aims to replicate these genetic mutations in stem cells, generating defective cartilage for comparison with normal cartilage. By analysing the

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued For the year ended 31 December 2023

RNA molecules responsible for protein coding, they hope to pinpoint the molecular-level issues in cartilage formation. This research is expected to identify key molecules causing the disease, potentially paving the way for future drug treatments.

- In 2023, Acrodysostosis Support & Research continues to collaborate with Great Ormond Street Hospital Children's Charity (GOSHCC) & Sparks, as part of their national funding call for 2020/21. This initiative is dedicated to advancing the understanding and treatment of rare diseases in children. The successful application was publicly announced in April 2021, and the grant was awarded to Professor Patrizia Ferretti at University College London (UCL). The primary objective of this partnership is to develop human models of acrodysostosis, with the goal of identifying specific druggable targets tailored to each patient's disease, aiming to normalize development in affected children and enhance their overall quality of life.

As a significant contributor to this venture, Acrodysostosis Support & Research did provide 25% of the project's total funding, equivalent to £62,500 in 2021. The organisation is delighted to confirm that this three-year research project commenced in the autumn of 2021. Regular communication between the charity and the research team ensures that the community stays updated on progress. Additionally, the charity remains open to exploring opportunities for future collaborative projects.

Raising Awareness:

- In March 2023 The charity attended, the Advanced Therapies Congress which is Europe's largest cell and gene therapy conference and exhibition in London. It's attended by 2,000 delegates, 100 exhibitors, 200 innovative young start-ups and 300 speakers from across the entire value chain of cell and gene therapy development; including forward-thinking pharma companies, researchers, clinicians, academics, HTAs, payers and regulators.

- In June 2023 The chair of the charity, Nina Knight, as a programme committee member for the EURORDIS Open Academy School went to Barcelona to attend and complete the Open Academy School on Scientific Innovation and Translational Research' as well as moderate one of the sessions. The school is attended by 100's of rare disease advocates as well as thought leaders including, researchers, clinicians, academics, HTAs, and regulators.

- In September 2023 Nina Knight the chair of the charity became an ePAG@ERN-ITHACA (patient advisory board member at the European reference network for rare malformation syndromes and rare intellectual and neurodevelopmental disorders). The role of ePAG is to represent the voice and interests of their patient community and act as the bridge between this community and the ERN. ePAG have an official permanent mandate to represent ePAG member organisations. They liaise with these organisations to ensure true and equitable representation of the patient voice by participating in the Board and sub-clinical committees of their respective ERN.

In October 2023 The charity attended The World Orphan Drug Congress Europe which is the largest and most established orphan drug & rare disease event worldwide. Where the charity had the opportunity to connect with more than 2000 attendees, 250 leading speakers, and 130 exhibitors, as they bring together experts from the start-to-finish of orphan drugs, from regulation and policy to global pricing and gene therapy.

- In October 2023 The Charity attended the 4th Annual MarketsandMarkets Orphan Drugs and Rare Diseases Conference in London, which aims to provide a valuable and broad platform to discuss recent advances in the development of life-saving therapies, critical issues, and strategies to enhance orphan drug development in near future. The conference brought together scientists, researchers, entrepreneurs, academicians, medical officials, and technologists across the globe to discuss the newest findings in the areas of rare diseases and orphan drugs, helping to shape present and upcoming challenges in drug analysis. It gave the charity the opportunity to interact with industry peers and participate in a scientific conference while staying informed about the most recent developments in the study of rare diseases.

- In November 2023 The charity attended the Rare Beacon <https://www.rarebeacon.org/> London Rare Disease Showcase' which aims to shed light on the latest innovations and advancements occurring in the field of rare diseases, with special emphasis on the vibrant rare disease landscape in the UK's capital.

Fundraising:

- The charity received a generous donation of £200 from a parent of a child with Acrodysostosis.

- The charity received £4755.27 in gift aid.

- Furthermore, in addition to the financial contributions from parents, patients, and friends of the charity, a substantial number of volunteer hours have been dedicated to Acrodysostosis Support & Research. These individuals have passionately supported families and remain steadfast in their commitment to advancing the scientific understanding of this disease. Their collective efforts are focused on expediting the development of viable treatments and, ideally, a cure in the future.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued
For the year ended 31 December 2023

FINANCIAL REVIEW

Financial review and reserves policy

The charity Trustees continually monitor cash reserves to ensure its financial stability.

Acrodysostosis Support & Research is committed to building a reserves policy to ensure there is enough funding to cover one year's operating costs.

The charity has no outstanding financial obligations nor outstanding debts. The charity's principal source of funds comes from the general public, either through donations or at one-off fundraising events.

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	ACRODYSOSTOSIS SUPPORT & RESEARCH
Charity registration number	1182818
Company registration number	CE017079
Principal address	Bath House, Cudworth Lane Newdigate Dorking Surrey SE15 5AF

Trustees

The trustees and officers serving during the year and since the year end were as follows:

Jan Sara Hine
Sarah Louise Denney
Nina Samantha Knight

Independent examiners

Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

Approved by the Board of Trustees and signed on its behalf by

DocuSigned by:

Mrs Nina Knight

.....25F8028178254B9.....

17 October 2024

Nina Samantha Knight

ACRODYSOSTOSIS SUPPORT & RESEARCH
Independent Examiners Report to the Trustees
For the year ended 31 December 2023

I report to the trustees on my examination of the accounts of the charitable company for the year ended 31 December 2023.

Responsibilities and basis of report

As the charity Trustees, who are also directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').


Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

DocuSigned by:

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Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

17 October 2024

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Activities (including Income and Expenditure Account)
For the year ended 31 December 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 £	2022 £
Income and endowments from:					
Donations and legacies	2	5,076	-	5,076	22,836
Total		5,076	-	5,076	22,836
Expenditure on:					
Raising funds	3	(255)	-	(255)	(257)
Charitable activities		(3,670)	-	(3,670)	(23,027)
Total		(3,925)	-	(3,925)	(23,284)
Net income/expenditure		1,151	-	1,151	(448)
Reconciliation of funds					
Total funds brought forward		31,232	3,417	34,649	35,097
Total funds carried forward		32,383	3,417	35,800	34,649

ACRODYSOSTOSIS SUPPORT & RESEARCH

Statement of Financial Position

As at 31 December 2023

	Notes	2023 £	2022 £
Current assets			
Debtors		431	207
Cash at bank and in hand		39,588	35,594
		40,019	35,801
Creditors: amounts falling due within one year	9	(4,219)	(1,152)
Net current assets		35,800	34,649
Total assets less current liabilities		35,800	34,649
Net assets		35,800	34,649
The funds of the charity			
Restricted income funds	10	3,417	3,417
Unrestricted income funds	10	32,383	31,232
Total funds		35,800	34,649

For the year ended 31 December 2023 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:

DocuSigned by:

Mrs Nina Knight

25F8028178254B9

Nina Samantha Knight

Trustee

17 October 2024

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements For the year ended 31 December 2023

1. Accounting Policies

Basis of accounting

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015), Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the (2011 or 2006 Act).

ACRODYSOSTOSIS SUPPORT & RESEARCH meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

The financial statements are prepared in sterling, which is the functional currency of the entity.

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

Funds

Unrestricted funds are incoming resources receivable or generated for the furtherance of the objectives of the Charity without a specified purpose and are available as general funds. Resources expended which meet these criteria are charged to the funds, together with a fair allocation of staff and support costs. Restricted funds are used for the specific purposes laid down by the donor or sponsor. Resources expended which meet these criteria are charged to the funds.

Taxation

The Charity is exempt from taxation on its charitable activities, as it is a registered charity.

Debtors

Debtors are recognised at the settlement amount due after allowing for any discounts and as per the terms agreed. Prepayments are valued at the amounts prepaid for services and accrued income are valued at the amounts due per terms agreed and there is certainty of receipt.

Income and interest receivable

Income is recognised in the period when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably and is not deferred.

Income received in advance of the provision of a specified service is deferred until the criteria for income recognition are met.

Income comprises of funds received from donations as well as gift aid,

The value of services provided by volunteers has not been included.

Other accounting policies

Cash at bank and in hand:

Cash at bank and cash in hand includes bank balance kept in current and deposit accounts.

Creditors and provisions:

Creditors and provisions 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 and provision are normally recognised at their settlement amount after allowing for any discounts.

Financial instruments:

The charity only has financial assets and financial liabilities of a kind that qualifies as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their amortised costs.

Critical accounting estimates and judgements:

There are no significant areas of judgement or key sources of estimation uncertainty arising from the preparation of accounts.

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2023

2. Income from donations and legacies

	2023	2022
	£	£
Unrestricted funds		
Donations received	321	817
Gifts in kind	4,755	-
Donated goods and services	-	22,019
	5,076	22,836
	5,076	22,836

3. Expenditure on generating donations and legacies

	2023	2022
	£	£
Unrestricted funds		
Support costs	255	257
	255	257
	255	257

4. Analysis of support costs

	2023	2022
	£	£
Governance costs		
Accountancy fees	963	576
Subscriptions	2,707	432
Insurance	255	257
	3,925	1,265
	3,925	1,265

It should be noted that subscriptions are higher this year as a backdated expense claim was made for 5 years of website costs. These costs had not previously been accrued for. In 2024 we expect subscription costs to be substantially lower.

Accountancy fees are higher this year due to an annual increase in fees as well as additional fees to claim for the gift aid refund which was received in the year.

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2023

5. Net income/(expenditure) for the year

This is stated after charging/(crediting):

	2023	2022
	£	£
Accountancy fees	963	576
	963	576

6. Staff costs and emoluments

	2023	2022
General staff	0	0
	0	0

7. Trustee remuneration and related party transactions

There are no disclosable reimbursements to trustees in this financial period.

All amounts reimbursed in the year to trustees related to costs for fulfilling their duties as trustees as well as the reimbursement of costs which relate to the furtherance of the charity's objectives.

It should be noted that this year there was a backdated claim for subscriptions which had not previously been accrued for.

8. Comparative for the Statement of Financial Activities

The comparative year values on the Statement of Financial Activities are for unrestricted funds.

9. Creditors: amounts falling due within one year

	2023	2022
	£	£
Other creditors	3,499	576
Accruals and deferred income	720	576
	4,219	1,152

Included in other creditors is an amount due to the trustees for expense claims. This amount should be repaid within 12 months of the year end.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements Continued

For the year ended 31 December 2023

10. Movement in funds

Unrestricted Funds

	Balance at 01/01/2023	Incoming resources	Outgoing resources	Balance at 31/12/2023
	£	£	£	£
<i>General</i>				
General	31,232	5,076	(3,925)	32,383
	<u>31,232</u>	<u>5,076</u>	<u>(3,925)</u>	<u>32,383</u>

Unrestricted Funds - Previous year

	Balance at 01/01/2022	Incoming resources	Outgoing resources	Balance at 31/12/2022
	£	£	£	£
<i>General</i>				
General	31,680	22,836	(23,284)	31,232
	<u>31,680</u>	<u>22,836</u>	<u>(23,284)</u>	<u>31,232</u>

Purpose of unrestricted Funds

General

To fulfil the principal objectives of the charity.

Restricted Funds

	Balance at 01/01/2023	Balance at 31/12/2023
	£	£
Family Day	3,417	3,417
	<u>3,417</u>	<u>3,417</u>

Restricted Funds - Previous year

	Balance at 01/01/2022	Balance at 31/12/2022
	£	£
Family Day	3,417	3,417
	<u>3,417</u>	<u>3,417</u>

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2023

Purpose of restricted funds

Family Day

Delivering a family day for attendees as prescribed by the donors.

11. Analysis of net assets between funds

	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
General	32,383	32,383
Restricted funds		
Family Day	3,417	3,417
	35,800	35,800
 Previous year		
	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
General	31,232	31,232
Restricted funds		
Family Day	3,417	3,417
	34,649	34,649

ACRODYSOSTOSIS SUPPORT & RESEARCH

Detailed Statement of Financial Activities

For the year ended 31 December 2023

	2023	2022
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	321	817
Gifts in kind	4,755	-
Donated goods and services	-	22,019
	<u>5,076</u>	<u>22,836</u>
Total incoming resources	5,076	22,836
EXPENDITURE		
Charitable activities		
Roundtable research meeting costs (Roundtable research meetings)	-	(22,019)
	<u>-</u>	<u>(22,019)</u>
SUPPORT COSTS		
Governance costs		
Governance costs	(255)	(257)
Governance costs (Donation collections)	(3,670)	(1,008)
	<u>(3,925)</u>	<u>(1,265)</u>
Total resources expended	(3,925)	(23,284)
Net Income	1,151	(448)

ACRODYSOSTOSIS SUPPORT & RESEARCH

England & Wales - Charity number 1182818

Accounts

Charity number: 1182818

(England and Wales)

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2022

ACRODYSOSTOSIS SUPPORT & RESEARCH

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ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees

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- follow applicable UK accounting standards and the Charities SORP FRS 102, disclosing and explaining any departures in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to do so.

The Trustees are responsible for maintaining 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 accounts comply with the Charities Act 2011 and with the requirements of the Statement of Recommended Practice Accounting and Reporting by Charities: statement of recommended practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) - Charities SORP FRS102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102). They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities besides the above responsibilities.

This report was approved by the trustees on 31st October 2023

OBJECTIVES AND ACTIVITIES

Charitable objectives:

To relieve the needs of those affected by Acrodysostosis by promoting greater understanding of the causes, symptoms, and treatment of Acrodysostosis in all its forms including:

- promoting research and sharing and disseminating of results of such research for the benefit of the general public; and
- raising public awareness of the symptoms, needs and related medical conditions of those living with Acrodysostosis

Charitable activities:

The Trustees ensure that sufficient attention is paid to fundraising activities, monitoring grant funding opportunities and manage the charity's assets to ensure its sustainability and ability to carry out its charitable objectives. The charity relies heavily on its volunteers as it has no paid members of staff.

Objectives and aims

The trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

The charity's objectives are to offer support and information to families affected by Acrodysostosis. Acrodysostosis Support & Research liaises closely with researchers at UCL Great Ormond St Hospital (UCL GOSH) with regards to the ongoing pioneering research into Acrodysostosis. Additionally, the charity is actively engaged in collaborative efforts with researchers from the University of Manchester, University of Glasgow and Keele University and also works constructively and in partnership with other agencies and organisations to continually improve support for families affected by Acrodysostosis - to change lives and make a difference to those living with the condition.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued
For the year ended 31 December 2022

ACHIEVEMENTS AND PERFORMANCE

Key activities and achievements throughout the year include:

Peer Support:

- One of the main aims of the charity is to bring together families and the Acrodysostosis community to share experiences and provide peer support through the Acrodysostosis network. The charity provides this support to their families via their ambassadors who are always available to listen and provide emotional and practical help to their Acrodysostosis Families.

- Acrodysostosis have continued to provide a range of information offering guidance and support for Acrodysostosis families.

General support:

Acrodysostosis families have found comfort from hearing and sharing experiences via the Acrodysostosis private Support Facebook group as well as various zoom meetings which any of the Acrodysostosis community could attend and get the opportunity to meet virtually.

Acrodysostosis Support & Research have continued to provide a range of information offering guidance and support for Acrodysostosis families including:

Medical Advisory Board (MAB):

The MAB was formed to guide the trustees in scientific matters, including research efforts and direction, and consists of renowned experts in the field. The MAB continues to meet regularly to facilitate the expanding body of knowledge around Acrodysostosis so families can be better supported - the trustees are very grateful to the MAB members for their dedication and commitment to helping Acrodysostosis families. The MAB along with Trustees and Ambassadors are continuing to take the lead in identifying research opportunities. And through a roundtable meeting which was sponsored by Costello medical the charity was able to bring together all the researchers, MAB, Trustee and Ambassadors to discuss the future landscape for research into Acrodysostosis with the aim of finding treatments.

Communications:

- Communications with those within the Acrodysostosis community and the general public through the Acrodysostosis website, and via social media.

- On Facebook a public page for the general public is used as their primary form of outbound communication. The charity also has a closed support group for families affected by the condition.

- Acrodysostosis also has active Twitter and Instagram pages.

Research:

- Acrodysostosis Support & Research is actively collaborating with its Medical Advisory Board (MAB) and the Acrodysostosis Community to introduce a global Acrodysostosis patient registry. Simultaneously, the charity has been diligently gathering data through the first-ever community survey. To further bolster this initiative, Costello Medical and Acrodysostosis Support & Research orchestrated and hosted a roundtable discussion, focusing on the patient registry and the future research landscape for Acrodysostosis. This meeting provided an opportunity to finalise the patient registry questions in preparation for its launch. Additionally, the gathering led to the establishment of a consortium comprising Researchers, Clinicians, Scientists, and the Board of trustees who are actively collaborating to identify and pursue research opportunities for Acrodysostosis.

- In June 2022, with the invaluable support of Acrodysostosis Support & Research, Professor Sue Kimber successfully secured her place as part of The UK Rare Disease Research Platform which has been established with a £14 million investment over five years by the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR). This represents a significant milestone in the ongoing efforts to advance the understanding of rare conditions including Acrodysostosis. Here is a summary:

"In patients with Acrodysostosis, genetic mutations disrupt the response of growth plate cartilage to hormones. A research team has developed a method to cultivate growth plate-like cartilage from stem cells and manipulate genes. Their project aims to replicate these genetic mutations in stem cells, generating defective cartilage for comparison with normal cartilage. By analysing the RNA molecules responsible for protein coding, they hope to pinpoint the molecular-level issues in cartilage formation. This research is expected to identify key molecules causing the disease, potentially paving the way for future drug treatments."

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued For the year ended 31 December 2022

- In 2021 Acrodysostosis Support and Research collaborated on a growth research project and a paper entitled "acrodysostosis: Growth patterns and OUTCOME ON growth hormone Therapy for short stature" by Ertl, Diana-Alexandra will be published 2023. The Chair and one of the Ambassadors will be included as co-authors.

- Dr Melissa Bowerman with the charity's support was successful with an application to GEMM aimed at generating one mouse model and this ACRDYS 2 mouse model has been generated and has been received into the labs in April 2022. As a result, of the roundtable meeting, Dr Melissa has started to collaborate with the other researchers. More funds will need to be raised to support the characterization of this GEMM-funded ACRDYS2 mouse model. This project is ongoing, but Dr Bowerman is now collaborating with other researchers from the Acrodysostosis Support & Research network.

- In 2022, Acrodysostosis Support & Research continues to collaborate with Great Ormond Street Hospital Children's Charity (GOSHCC) & Sparks, as part of their national funding call for 2020/21. This initiative is dedicated to advancing the understanding and treatment of rare diseases in children. The successful application was publicly announced in April 2021, and the grant was awarded to Professor Patrizia Ferretti at University College London (UCL).

The primary objective of this partnership is to develop human models of acrodysostosis, with the goal of identifying specific druggable targets tailored to each patient's disease, aiming to normalize development in affected children and enhance their overall quality of life.

As a significant contributor to this venture, Acrodysostosis Support & Research has provided 25% of the project's total funding, equivalent to £62,500.

The organisation is delighted to confirm that this three-year research project commenced in the autumn of 2021. Regular communication between the charity and the research team ensures that the community stays updated on progress. Additionally, the charity remains open to exploring opportunities for future collaborative projects.

Raising Awareness:

- A Parent, Advocate, Ambassador; Kym Stanley in the UK has again through the organisation Medics 4 Rare Disease collaborated with a medical student to write an essay on Acrodysostosis for an essay competition.

- Kymie Gleeson, a dedicated parent, advocate, and Ambassador, based in Australia, has devoted the year to actively promoting awareness for Acrodysostosis Support & Research. She accomplished this through her own foundation, which provides vital support to young people with disabilities and their families.

- Nina Knight, the Chair of Acrodysostosis, delivered a presentation to young students at a school in Spain, raising awareness about Acrodysostosis and rare diseases as a whole. Her efforts aimed to inspire young individuals considering careers in medicine to explore the field of rare disease including Acrodysostosis.

Fundraising:

- In May 2022, Costello Medical organised and hosted a multi-stakeholder roundtable meeting, involving researchers, clinicians, and caregivers, in partnership with Acrodysostosis Support and Research. It is noteworthy that this undertaking was conducted on a pro bono basis and carried an estimated value of £22,018.75. For more details, please refer to the attached proposal.

- A substantial portion of the fundraising efforts have taken the form of the charity providing invaluable support to researchers throughout the grant application process. For instance, the charity can highlight the noteworthy success of Professor Sue Kimber, who was awarded a prestigious grant by the MRC & NIHR with the charity's assistance.

- The charity received a generous donation of £150 following the passing of a trustee's father.

- Furthermore, in addition to the financial contributions from parents, patients, and friends of the charity, a substantial number of volunteer hours have been dedicated to Acrodysostosis Support & Research. These individuals have passionately supported families and remain steadfast in their commitment to advancing the scientific understanding of this disease. Their collective efforts are focused on expediting the development of viable treatments and, ideally, a cure in the future.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued
For the year ended 31 December 2022

FINANCIAL REVIEW

Financial review and reserves policy

The charity Trustees continually monitor cash reserves to ensure its financial stability.

Acrodysostosis Support & Research is committed to building a reserves policy to ensure there is enough funding to cover one year's operating costs.

The charity has no outstanding financial obligations nor outstanding debts. The charity's principal source of funds comes from the general public, either through donations or at one-off fundraising events.

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	ACRODYSOSTOSIS SUPPORT & RESEARCH
Charity registration number	1182818
Principal address	Bath House, Cudworth Lane Newdigate Dorking Surrey SE15 5AF

Trustees

The trustees and officers serving during the year and since the year end were as follows:

Jan Sara Hine
Sarah Louise Denney
Nina Samantha Knight

Independent examiners

Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

Approved by the Board of Trustees and signed on its behalf by

DocuSigned by:


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31 October 2023

Nina Samantha Knight

ACRODYSOSTOSIS SUPPORT & RESEARCH
Independent Examiners Report to the Trustees
For the year ended 31 December 2022

I report to the trustees on my examination of the accounts of the charitable company for the year ended 31 December 2022.

Responsibilities and basis of report

As the charity Trustees, who are also directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

DocuSigned by:


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Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

31 October 2023

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Activities (including Income and Expenditure Account)
For the year ended 31 December 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 £	2021 £
Income and endowments from:					
Donations and legacies	2	22,836	-	22,836	12,391
Total		22,836	-	22,836	12,391
Expenditure on:					
Raising funds	3	(257)	-	(257)	(62,742)
Charitable activities		(23,027)	-	(23,027)	(576)
Total		(23,284)	-	(23,284)	(63,318)
Net income/expenditure		(448)	-	(448)	(50,927)
Reconciliation of funds					
Total funds brought forward		31,680	3,417	35,097	86,024
Total funds carried forward		31,232	3,417	34,649	35,097

ACRODYSOSTOSIS SUPPORT & RESEARCH

Statement of Financial Position

As at 31 December 2022

	Notes	2022 £	2021 £
Current assets			
Debtors		207	63
Cash at bank and in hand		35,594	35,610
		35,801	35,673
Creditors: amounts falling due within one year	9	(1,152)	(576)
Net current assets		34,649	35,097
Total assets less current liabilities		34,649	35,097
Net assets		34,649	35,097
The funds of the charity			
Restricted income funds	10	3,417	3,417
Unrestricted income funds	10	31,232	31,680
Total funds		34,649	35,097

For the year ended 31 December 2022 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:

DocuSigned by:

Mrs Nina Knight

26F3028478254B9...

Nina Samantha Knight
Trustee

31 October 2023

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements
For the year ended 31 December 2022**1. Accounting Policies****Basis of accounting**

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the Companies Act 2006.

ACRODYSOSTOSIS SUPPORT & RESEARCH meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

2. Income from donations and legacies

	2022	2021
	£	£
Unrestricted funds		
Donations received	817	12,391
Donated goods and services	22,019	-
	<u>22,836</u>	<u>12,391</u>

This includes income of donated services on a pro bono basis from Costello Medical for the hosting and provision of professional fees necessary to run the meeting.

3. Expenditure on generating donations and legacies

	2022	2021
	£	£
Unrestricted funds		
Donations	-	62,500
Support costs	257	242
	<u>257</u>	<u>62,742</u>

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2022

4. Analysis of support costs

	2022	2021
	£	£
Advertising		
Advertising	-	159
Governance costs		
Accountancy fees	576	576
Subscriptions	432	49
Exchange (Profit)/Loss	-	(341)
Insurance	257	194
Subscriptions	-	181
	<u>1,265</u>	<u>659</u>
	<u>1,265</u>	<u>818</u>

5. Net income/(expenditure) for the year

This is stated after charging/(crediting):

	2022	2021
	£	£
Accountancy fees	576	576
	<u>576</u>	<u>576</u>

6. Staff costs and emoluments

	2022	2021
General staff	0	0
	<u>0</u>	<u>0</u>

7. Trustee remuneration and related party transactions

The only diclosable tranasction with related parties is an expense reimbursement creditor to the Trustee Nina Knight for payment of charity subscriptions costs.
These will be repaid to the trustee after the year end.

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2022

8. Comparative for the Statement of Financial Activities

	Unrestricted funds £	Restricted funds £	2021 £
Income and endowments from:			
Donations and legacies	8,974	3,417	12,391
Total	8,974	3,417	12,391
Expenditure on:			
Raising funds	(62,659)	-	(62,659)
Charitable activities	(576)	-	(576)
Total	(63,235)	-	(63,235)
Net income/expenditure	(54,261)	3,417	(50,844)
Reconciliation of funds			
Total funds brought forward	86,024	-	86,024
Total funds carried forward	31,763	3,417	35,180

9. Creditors: amounts falling due within one year

	2022 £	2021 £
Other creditors	576	-
Accruals and deferred income	576	576
	1,152	576

10. Movement in funds**Unrestricted Funds**

	Balance at 01/01/2022 £	Incoming resources £	Outgoing resources £	Balance at 31/12/2022 £
<i>General</i>				
General	31,680	22,836	(23,284)	31,232
	31,680	22,836	(23,284)	31,232

Unrestricted Funds - Previous year

	Balance at 01/01/2021 £	Incoming resources £	Outgoing resources £	Balance at 31/12/2021 £
<i>General</i>				
General	86,024	8,974	(63,318)	31,680
	86,024	8,974	(63,318)	31,680

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2022

Purpose of unrestricted Funds

General

To fulfil the principal objectives of the charity.

Restricted Funds

	Balance at 01/01/2022	Incoming resources	Balance at 31/12/2022
	£	£	£
Family Day	3,417	-	3,417
	<u>3,417</u>	<u>-</u>	<u>3,417</u>

Restricted Funds - Previous year

	Balance at 01/01/2021	Incoming resources	Balance at 31/12/2021
	£	£	£
Family Day	-	3,417	3,417
	<u>-</u>	<u>3,417</u>	<u>3,417</u>

Purpose of restricted funds

Family Day

Delivering a family day for attendees as prescribed by the donors.

11. Analysis of net assets between funds

	Net current assets / (liabilities)	Net Assets
	£	£
Unrestricted funds		
<i>General</i>		
General	31,232	31,232
Restricted funds		
Family Day	3,417	3,417
	<u>34,649</u>	<u>34,649</u>

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2022

Previous year

	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
General	31,680	31,680
Restricted funds		
Family Day	3,417	3,417
	35,097	35,097
	35,097	35,097

ACRODYSOSTOSIS SUPPORT & RESEARCH

Detailed Statement of Financial Activities

For the year ended 31 December 2022

	2022	2021
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	817	12,391
Donated goods and services	22,019	-
	22,836	12,391
Total incoming resources	22,836	12,391
EXPENDITURE		
Raising donations and legacies		
Donations	-	(62,500)
	-	(62,500)
Charitable activities		
Roundtable research meeting costs (Roundtable research meetings)	(22,019)	-
	(22,019)	-
SUPPORT COSTS		
Advertising		
Advertising	-	(159)
	-	(159)
Governance costs		
Governance costs	(257)	(83)
Governance costs (Donation collections)	(1,008)	(576)
	(1,265)	(659)
Total resources expended	(23,284)	(63,318)
Net Expenditure	(448)	(50,927)

ACRODYSOSTOSIS SUPPORT & RESEARCH

England & Wales - Charity number 1182818

Accounts

Charity number: 1182818

(England and Wales)

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2021

ACRODYSOSTOSIS SUPPORT & RESEARCH

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For the year ended 31 December 2021

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Detailed Statement of Financial Activities	13

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees

For the year ended 31 December 2021

The Trustees, who are also directors for the purposes of company law, have pleasure in presenting their report and the financial statements for the charitable company for the year ended 31 December 2021. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2015).

OBJECTIVES AND ACTIVITIES

Charitable objectives:

To relieve the needs of those affected by Acrodysostosis by promoting greater understanding of the causes, symptoms, and treatment of Acrodysostosis in all its forms including:

- promoting research and sharing and disseminating of results of such research for the benefit of the general public; and

- raising public awareness of the symptoms, needs and related medical conditions of those living with Acrodysostosis

Charitable activities:

The Trustees ensure that sufficient attention is paid to fundraising activities, monitoring grant funding opportunities and manage the charity's assets to ensure its sustainability and ability to carry out its charitable objectives. The charity relies heavily on its volunteers as it has no paid members of staff. In 2021 three more Ambassadors from the Acrodysostosis community were added to the team the charity now have 6 in total. They are made up of patients with Type 1 and 2 as well as parents, and their main role is to raise awareness of the condition.

Objectives and aims

The trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

The charity's objectives are to offer support and information to families affected by Acrodysostosis.

Acrodysostosis Support & Research liaises closely with researchers at UCL Great Ormond St Hospital (UCL GOSH) with regards to the ongoing pioneering research into Acrodysostosis. It also works constructively and in partnership with other agencies and organisations to continually improve support for families affected by Acrodysostosis - to change lives and make a difference to those living with the condition.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued For the year ended 31 December 2021

ACHIEVEMENTS AND PERFORMANCE

Key activities and achievements throughout the year include:

Peer Support:

- One of the main aims of the charity is to bring together families and the Acrodysostosis community to share experiences and provide peer support through the Acrodysostosis network. The charity provide this support to their families via their ambassadors who are always available to listen and provide emotional and practical help to their Acrodysostosis Families.
- Acrodysostosis have continued to provide a range of information offering guidance and support for Acrodysostosis families.

Covid-19:

Acrodysostosis families have found comfort from hearing and sharing experiences via the Acrodysostosis private Support Facebook group as well as various zoom meetings which any of the Acrodysostosis community could attend and get the opportunity to meet virtually.

Acrodysostosis Support & Research have continued to provide a range of information offering guidance and support for Acrodysostosis families including

Medical Advisory Board (MAB):

The MAB was formed to guide the trustees in scientific matters, including research efforts and direction, and consists of renowned experts in the field. The MAB continues to meet regularly to facilitate the expanding body of knowledge around Acrodysostosis so families can be better supported - the trustees are very grateful to the MAB members for their dedication and commitment to helping Acrodysostosis families. The MAB along with Trustees and Ambassadors take the lead in identifying research opportunities.

Communications:

- Communications with those within the Acrodysostosis community and the general public through the Acrodysostosis website, and via social media.
- On Facebook a public page for the general public is used as their primary form of outbound communication. The charity also have a closed support group for families affected by the condition.
- Acrodysostosis also has active Twitter and Instagram pages.

Research:

- In 2020 Acrodysostosis Support & Research formally entered into a research partnership with Great Ormond Street Hospital Children's Charity (GOSHCC) & Sparks for its national funding call 2020/21, which aims to tackle the understanding and treatment of rare diseases in children. The successful application was announced in the April 2021 and was awarded to Prof. Patrizia Ferretti at UCL the aim of which is to establish human models of acrodysostosis to select disease/patient-specific druggable targets aimed at normalizing development in affected children, hence improving their quality of life. As part of the partnership, Acrodysostosis Support & Research has provided 25% (£62,500) of the project costs. The charity are delighted to confirmed that that this 3 year research project started in the Autumn of 2021. The charity are in regular contact with the research team who provide them and their community with updates and the charity are already looking for ways to partner on other projects in the future.
- Acrodysostosis Support & Research continue to work with it's MAB, Acrodysostosis Community and OpenApp to launch a global Acrodysostosis patient registry, in the meantime the charity have been busy collecting data from the community in the first survey of its kind.
- Acrodysostosis Support and Research collaborated on a growth research project and a paper entitled "acrodysostosis: Growth patterns and OUTCOME ON growth hormone Therapy for short stature" by Ertl, Diana-Alexandra will be published soon. The Chair and one of the Ambassadors will be included as co-authors.
- Dr Melissa Bowerman with the charity's support was successful with an application to GEMM aimed at generating one mouse model and this ACRDYS 2 mouse model is currently being generated and should be received in the lab by the end of the 2021. Funds will need to be raised to support the characterization of this GEMM-funded ACRDYS2 mouse model.

Raising Awareness:

- In July 2021 the Chair Nina Knight did a video interview with Shannon Gunn for the Line Genomics Series.

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees Continued For the year ended 31 December 2021

- A Parent, Advocate, Ambassador; Kymie Gleeson in Australia in several articles for local publications; Source Magazine print 10K and 37K digital subscribers, Take 5 magazine circulation 15K per month and 75K digital subscribers.
- A Parent, Advocate, Ambassador; Kym Stanley in the UK through the organisation Medics 4 Rare Disease collaborated with a medical student to write an essay on Acrodysostosis for an essay competition.

Fundraising:

- Much of the fundraising for 2021 was cancelled due to the continued COVID-19 pandemic. Acrodysostosis Support & Research's Crowdfunding Project continued to raise money for January & February 2021. The final total raised from this project was £90K. This project enlisted the support of 70 families affected by acrodysostosis, who all fundraised in 32 countries, and they got 1500 supporters who donated. This was a huge success Acrodysostosis Support & Research the charity is very grateful to everyone who took part. All funds from this project have been and will continue to be used for research or improving the lives of those affected by Acrodysostosis.
- In January 2021 the charity was awarded £3416.66 from Genetic Disorders for the GDUK Grant this has been allocated for a family day.
- In Feb 2021 Chubb Services donated £500.00 towards research.
- In July 2021, 3 baccalaureate students, Yu Ru Liu, Shailin Katebiyan & Isabel Van der Burg from Aloha College in Marbella as part of their SECCA, chose Acrodysostosis Support and Research and the Debra Charity as charities they wanted to support and they hosted a charity gala which raised £3783.52 for Acrodysostosis Support & Research.
- In October 2021 Costello Medical carried out £13774.00 worth of work for Acrodysostosis Support & Research on a pro bono basis, with their time they created a health care professional information leaflet. This leaflet has been completed in collaboration with the Acrodysostosis community, the MAB and Costello Medical. It's the first of kind and will be used as a tool to inform HCP's, Acrodysostosis Families and to raise awareness.
- In October 2021 Julie Blunt a private donor, gifted £1000.00 to Acrodysostosis Support & Research.
- In addition to the funds raised parents, patients and friends of the charity have volunteered 100's of hours to work for Acrodysostosis Support & Research in their roles to support the families and these same people are constantly on a quest to promote the acceleration of the science for this disease, so that one day there will be viable treatments and perhaps a cure.

FINANCIAL REVIEW

Financial review and reserves policy:

The charity Trustees continually monitor cash reserves to ensure its financial stability.

Acrodysostosis Support & Research is committed to building a reserves policy to ensure there is enough funding to cover one year's operating costs, the expenses for one family meet up per year and to fund research opportunities.

The charity has no outstanding financial obligations nor outstanding debts. The charity's principal source of funds comes from the general public, either through donations or at one-off fundraising events.

Going concern

The Trustees have assessed the charity's finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	ACRODYSOSTOSIS SUPPORT & RESEARCH
Charity registration number	1182818
Principal address	Bath House, Cudworth Lane Newdigate Dorking Surrey SE15 5AF

ACRODYSOSTOSIS SUPPORT & RESEARCH
Report of the Trustees Continued
For the year ended 31 December 2021

Trustees

The trustees and officers serving during the year and since the year end were as follows:

Jan Sara Hine
Sarah Louise Denney
Nina Samantha Knight

Independent examiners

Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

Approved by the Board of Trustees and signed on its behalf by

DocuSigned by:
Mrs Nina Knight
25F8028178254B9...

31 October 2022

.....
Nina Samantha Knight

ACRODYSOSTOSIS SUPPORT & RESEARCH
Independent Examiners Report to the Trustees
For the year ended 31 December 2021

I report to the trustees on my examination of the accounts of the charitable company for the year ended 31 December 2021.

Responsibilities and basis of report

As the charity Trustees, who are also directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

.....
Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

31 October 2022

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Activities (including Income and Expenditure Account)
For the year ended 31 December 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 £	2020 £
Income and endowments from:					
Donations and legacies	2	8,974	3,417	12,391	89,873
Total		8,974	3,417	12,391	89,873
Expenditure on:					
Raising funds	3	(62,742)	-	(62,742)	(3,309)
Charitable activities	4/5	(576)	-	(576)	(540)
Total		(63,318)	-	(63,318)	(3,849)
Net income/expenditure		(54,344)	3,417	(50,927)	86,024
Reconciliation of funds					
Total funds brought forward		86,024	-	86,024	-
Total funds carried forward		31,680	3,417	35,097	86,024

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Position
As at 31 December 2021

	Notes	2021 £	2020 £
Current assets			
Debtors	11	63	-
Cash at bank and in hand		35,610	86,564
		<u>35,673</u>	<u>86,564</u>
Creditors: amounts falling due within one year	12	(576)	(540)
Net current assets		<u>35,097</u>	<u>86,024</u>
Total assets less current liabilities		<u>35,097</u>	<u>86,024</u>
Net assets		<u>35,097</u>	<u>86,024</u>
The funds of the charity			
Restricted income funds	13	3,417	-
Unrestricted income funds	13	31,680	86,024
Total funds		<u>35,097</u>	<u>86,024</u>

For the year ended 31 December 2021 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:

DocuSigned by:

Mrs Nina Knight

 Nina Samantha Knight
 Trustee

31 October 2022

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements

For the year ended 31 December 2021

1. Accounting Policies**Basis of accounting**

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the Companies Act 2006.

ACRODYSOSTOSIS SUPPORT & RESEARCH meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

2. Income from donations and legacies

	Unrestricted funds	Restricted funds	2021	2020
	£	£	£	£
Donations received	8,974	3,417	12,391	89,873
	8,974	3,417	12,391	89,873

3. Expenditure on generating donations and legacies

	2021	2020
	£	£
Unrestricted funds		
Donations	62,500	-
Support costs	242	3,309
	62,742	3,309

4. Costs of charitable activities by fund type

	2021	2020
	£	£
Unrestricted funds		
Support costs	576	540

5. Costs of charitable activities by activity type

	2021	2020
	£	£
Donation collections	576	540

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2021

6. Analysis of support costs

	2021	2020
	£	£
Advertising		
Advertising	159	-
Governance costs		
Accountancy fees	576	540
Collection fees	-	2,012
Partner fees	49	1,158
Exchange (Profit)/Loss	(341)	139
Insurance	194	-
Subscriptions	181	-
	659	3,849
	818	3,849

7. Net income/(expenditure) for the year

This is stated after charging/(crediting):

	2021	2020
	£	£
Accountancy fees	576	540
	576	540

8. Staff costs and emoluments

	2021	2020
General staff	0	0
	0	0

9. Trustee remuneration and related party transactions

There are no disclosable transactions with related parties that occurred in the year.

ACRODYSSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2021

10. Comparative for the Statement of Financial Activities

The comparative year values on the Statement of Financial Activities are for unrestricted funds.

11. Debtors

	2021	2020
	£	£
Amounts due within one year:		
Prepayments and accrued income	63	-
	<u>63</u>	<u>-</u>

12. Creditors: amounts falling due within one year

	2021	2020
	£	£
Accruals and deferred income	576	540
	<u>576</u>	<u>540</u>

13. Movement in funds**Unrestricted Funds**

	Balance at 01/01/2021	Incoming resources	Outgoing resources	Balance at 31/12/2021
	£	£	£	£
<i>General</i>				
General	86,024	8,974	(63,318)	31,680
	<u>86,024</u>	<u>8,974</u>	<u>(63,318)</u>	<u>31,680</u>

Unrestricted Funds - Previous year

	Balance at 01/01/2020	Incoming resources	Outgoing resources	Balance at 31/12/2020
	£	£	£	£
<i>General</i>				
General	-	89,873	(3,849)	86,024
	<u>-</u>	<u>89,873</u>	<u>(3,849)</u>	<u>86,024</u>

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2021

Purpose of unrestricted Funds

General

To fulfil the principal objectives of the charity.

Restricted Funds

	Incoming resources	Balance at 31/12/2021
	£	£
Family Day	3,417	3,417
	<u>3,417</u>	<u>3,417</u>

Restricted Funds - Previous year

	Incoming resources	Balance at 31/12/2020
	£	£
	-	-
	<u>-</u>	<u>-</u>

Purpose of restricted funds

Family Day

Delivering a family day for attendees as prescribed by the donors.

14. Analysis of net assets between funds

	Net current assets / (liabilities)	Net Assets
	£	£
Unrestricted funds		
<i>General</i>		
General	31,680	31,680
Restricted funds		
Family Day	3,417	3,417
	<u>35,097</u>	<u>35,097</u>

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2021

Previous year

	Net current assets / (liabilities) £	Net Assets £
--	---	-----------------

Unrestricted funds

General

General

86,024

86,024

Restricted funds

86,024

86,024

ACRODYSOSTOSIS SUPPORT & RESEARCH
Detailed Statement of Financial Activities
For the year ended 31 December 2021

	2021	2020
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	12,391	89,873
	12,391	89,873
Total incoming resources	12,391	89,873
EXPENDITURE		
Raising donations and legacies		
Donations	(62,500)	-
	(62,500)	-
SUPPORT COSTS		
Advertising		
Advertising	(159)	-
	(159)	-
Governance costs		
Governance costs	(83)	(3,309)
Governance costs	(576)	(540)
	(659)	(3,849)
Total resources expended	(63,318)	(3,849)
Net Expenditure	(50,927)	86,024

ACRODYSOSTOSIS SUPPORT & RESEARCH

England & Wales - Charity number 1182818

Accounts

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees

For the year ending 31 December 2020

The Trustees have pleasure in presenting their report and the financial statements for the charity for the year ended 31 December 2020. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2015).

Structure, governance and management

Acrodysostosis Support & Research was established as a Charitable Incorporated Organisation on 5th of April 2019 and is managed by the Board of Trustees.

Objectives and charitable activities

Charitable objectives

To relieve the needs of those affected by Acrodysostosis by promoting greater understanding of the causes, symptoms, and treatment of Acrodysostosis in all its forms including:

- promoting research and sharing and disseminating of results of such research for the benefit of the general public; and
- raising public awareness of the symptoms, needs and related medical conditions of those living with Acrodysostosis

Charitable activities

The Trustees ensure that sufficient attention is paid to fundraising activities, monitoring grant funding opportunities and manage the charity's assets to ensure its sustainability and ability to carry out its charitable objectives. The charity relies heavily on its volunteers as it has no paid members of staff. In 2020 three Ambassadors from the Acrodysostosis community were added to our team to raise awareness of the condition.

Public benefit

In exercising their duty, the Trustees confirm that they have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

Our objectives are to offer support and information to families affected by Acrodysostosis. Acrodysostosis Support & Research liaises closely with researchers at UCL Great Ormond St Hospital (UCL GOSH) with regards to the upcoming pioneering research into Acrodysostosis. It also works constructively and in partnership with other agencies and organisations to continually improve support for families affected by Acrodysostosis - to change lives and make a difference to those living

with the condition.

Summary of activities, achievement and performance

Key activities and achievements throughout the year include:

Peer Support

- One of the main aims of the charity is to bring together families and the Acrodysostosis community to share experiences and provide peer support through the Acrodysostosis network. We provide this support to our families via our ambassadors who are always available to listen and provide emotional and practical help to our Acrodysostosis Families.
- Acrodysostosis have continued to provide a range of information offering guidance and support for Acrodysostosis families.

Covid-19

Acrodysostosis families have found comfort from hearing and sharing experiences via the Acrodysostosis private Support Facebook group as well as various zoom meetings which any of the Acrodysostosis community could attend and get the opportunity to meet virtually.

Acrodysostosis Support & Research have continued to provide a range of information offering guidance and support for Acrodysostosis families including

Medical Advisory Board (MAB)

The MAB was formed to guide the trustees in scientific matters, including research efforts and direction, and consists of renowned experts in the field. The MAB continues to meet regularly to facilitate the expanding body of knowledge around Acrodysostosis so families can be better supported - the trustees are very grateful to the MAB members for their dedication and commitment to helping Acrodysostosis families. The MAB along with Trustee and Ambassadors take the lead in identifying research opportunities.

Communications

- Communications with those within the Acrodysostosis community and the general public through the Acrodysostosis website, and via social media.
- On Facebook a public page for the general public is used as our primary form of outbound communication. We also have a closed support group for families affected by the condition.
- Acrodysostosis also has active Twitter and Instagram pages.

Research

- In 2020 Acrodysostosis Support & Research formally entered into a research partnership with Great Ormond Street Hospital Children's Charity (GOSHCC) & Sparks for its national funding call 2020/21, which aims to tackle the understanding and treatment of rare diseases in children. The successful application was announced in the April 2021 and was awarded to Prof. Patrizia Ferretti at UCL the aim of which is to establish human models of acrodysostosis to select disease/patient-specific druggable targets aimed at normalizing development in

affected children, hence improving their quality of life. As part of the partnership, Acrodysostosis Support & Research will provide 25% (£62,500) of the project costs.

- The diagnosis and management of pseudohypoparathyroidism and related disorders: first international Consensus Statement was published in Nature <https://www.nature.com/articles/s41574-018-0042-0> with assistance of parents from the Acrodysostosis community.
- Acrodysostosis Support & Research continue to work with it's MAB, Acrodysostosis Community and OpenApp to set up a global Acrodysostosis patient registry.

Raising Awareness

- In November 2020 Olivia Colman academy award winning actress pledged her support to the Acrodysostosis community by recording a video for Acrodysostosis Support & Research. Which reached thousands of people.
- In November Acrodysostosis Support & Research Ambassador Kimberley and her daughter Frankie were featured on the BBC's 6 O'clock news raising awareness for our community and speaking about their own personal story an average of 4 million people watch it daily.
- In November 2020 trustee Nina Knight did an article for the Nottingham post both online and in the paper to raise awareness of Acrodysostosis. The paper circulation is £15K and the online reach is 38.6million each month.

Fundraising

- Much of our fundraising for 2020 was cancelled due to the COVID-19 pandemic. Instead Acrodysostosis Support & Research planned and completed a Crowdfunding Project. They enlisted the support of 70 families affected by acrodysostosis, who all fundraised in 32 countries, and they got 1500 supporters who donated. This was a huge success Acrodysostosis Support & Research raised £74K in 30 days and are grateful to everyone who took part.
- The rest of the fundraising was done by individual supporters through 'Just Giving' who organised, knitting competitions, fun runs and one child even auctioned her sweets.

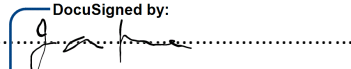
Financial review and reserves policy

The charity Trustees continually monitor cash reserves to ensure its financial stability.

Acrodysostosis Support & Research is committed to building a reserves policy to ensure there is enough funding to cover one year's operating costs, the expenses for one family meet up per year and to fund research opportunities.

The charity has no outstanding financial obligations nor outstanding debts. The charity's principal source of funds comes from the general public, either through donations or at one-off fundraising events.

Approved by the Board of Trustees and signed on its behalf by:

DocuSigned by:

Jan Sara Hill

29 October 2021

Charity number: 1182818

(England and Wales)

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2020

ACRODYSOSTOSIS SUPPORT & RESEARCH

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For the year ended 31 December 2020

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ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees

For the year ended 31 December 2020

The Trustees, who are also directors for the purposes of company law, have pleasure in presenting their report and the financial statements for the charitable company for the year ended 31 December 2020. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2015).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

FINANCIAL REVIEW

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	ACRODYSOSTOSIS SUPPORT & RESEARCH
Charity registration number	1182818
Principal address	Bath House, Cudworth Lane Newdigate Dorking Surrey SE15 5AF

Trustees

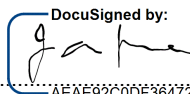
The trustees and officers serving during the year and since the year end were as follows:

Jan Sara Hine
Sarah Louise Denney

Independent examiners

Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

Approved by the Board of Trustees and signed on its behalf by

DocuSigned by:


.....
AFAE92C0DF36472...

29 October 2021

Jan Sara Hine

ACRODYSOSTOSIS SUPPORT & RESEARCH
Independent Examiners Report to the Trustees
For the year ended 31 December 2020

I report to the trustees on my examination of the accounts of the charitable company for the year ended 31 December 2020.

Responsibilities and basis of report

As the charity Trustees, who are also directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

DocuSigned by:

Garvin Spencer

Beach Accountants Limited

Chartered Certified Accountants

10 Blue Sky Way

Monkton Business Park South

South Tyneside

NE31 2EQ

29 October 2021

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Activities (including Income and Expenditure Account)
For the year ended 31 December 2020

	Notes	Unrestricted funds £	2019 £
Income and endowments from:			
Donations and legacies	2	89,873	-
Total		<u>89,873</u>	<u>-</u>
Expenditure on:			
Raising funds	3	(3,309)	-
Charitable activities	4/5	(540)	-
Total		<u>(3,849)</u>	<u>-</u>
Net income/expenditure		<u>86,024</u>	<u>-</u>
Total funds carried forward		<u>86,024</u>	<u>-</u>

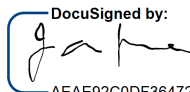
ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Position
As at 31 December 2020

	Notes	2020 £	2019 £
Current assets			
Cash at bank and in hand		86,564	-
		86,564	-
Creditors: amounts falling due within one year	10	(540)	-
Net current assets		86,024	-
Total assets less current liabilities		86,024	-
Net assets		86,024	-
The funds of the charity			
Unrestricted income funds	11	86,024	-
Total funds		86,024	-

For the year ended 31 December 2020 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:

DocuSigned by:


AEAE92C0DF36472

Jan Sara Hine
Trustee

29 October 2021

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements

For the year ended 31 December 2020

1. Accounting Policies**Basis of accounting**

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the Companies Act 2006.

ACRODYSOSTOSIS SUPPORT & RESEARCH meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

2. Income from donations and legacies

	2020	2019
	£	£
Unrestricted funds		
Donations received	89,873	-
	<u>89,873</u>	<u>-</u>

3. Expenditure on generating donations and legacies

	2020	2019
	£	£
Unrestricted funds		
Support costs	3,309	-
	<u>3,309</u>	<u>-</u>

4. Costs of charitable activities by fund type

	2020	2019
	£	£
Unrestricted funds		
Support costs	540	-

5. Costs of charitable activities by activity type

	2020	2019
	£	£
Donation collections	540	-

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2020

6. Analysis of support costs

	2020	2019
	£	£
Governance costs		
Accountancy fees	540	-
Collection fees	2,012	-
Partner fees	1,158	-
Exchange (Profit)/Loss	139	-
	3,849	-

7. Net income/(expenditure) for the year

This is stated after charging/(crediting):

	2020	2019
	£	£
Accountancy fees	540	-
	540	-

8. Staff costs and emoluments

	2020	2019
General staff	0	0
	0	0

9. Trustee remuneration and related party transactions

There were no transactions with trustees or other related parties that required disclosure in this current financial period.

10. Creditors: amounts falling due within one year

	2020	2019
	£	£
Accruals and deferred income	540	-
	540	-

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2020

11. Movement in funds**Unrestricted Funds**

	Incoming resources	Outgoing resources	Balance at 31/12/2020
	£	£	£
<i>General</i>			
General	89,873	(3,849)	86,024
	<u>89,873</u>	<u>(3,849)</u>	<u>86,024</u>

Unrestricted Funds - Previous year

	Incoming resources	Outgoing resources	Balance at 31/12/2019
	£	£	£
<i>General</i>			
	<u>-</u>	<u>-</u>	<u>-</u>

Purpose of unrestricted Funds

General

To fulfil the principal objectives of the charity.

12. Analysis of net assets between funds

	Net current assets / (liabilities)	Net Assets
	£	£
Unrestricted funds		
<i>General</i>		
General	86,024	86,024
	<u>86,024</u>	<u>86,024</u>

Previous year

	Net current assets / (liabilities)	Net Assets
	£	£
Unrestricted funds		
<i>General</i>		
	<u>-</u>	<u>-</u>

ACRODYSOSTOSIS SUPPORT & RESEARCH
Detailed Statement of Financial Activities
For the year ended 31 December 2020

	2020	2019
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	89,873	-
	<hr/> 89,873	<hr/> -
Total incoming resources	<hr/> 89,873	<hr/> -
SUPPORT COSTS		
Governance costs		
Governance costs	(3,309)	-
Governance costs	(540)	-
	<hr/> (3,849)	<hr/> -
Total resources expended	<hr/> (3,849)	<hr/> -
Net Income	<hr/> 86,024 <hr/>	<hr/> - <hr/>

Charity number: 1182818

(England and Wales)

ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2020

ACRODYSOSTOSIS SUPPORT & RESEARCH

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For the year ended 31 December 2020

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ACRODYSOSTOSIS SUPPORT & RESEARCH

Report of the Trustees

For the year ended 31 December 2020

The Trustees, who are also directors for the purposes of company law, have pleasure in presenting their report and the financial statements for the charitable company for the year ended 31 December 2020. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2015).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

FINANCIAL REVIEW

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	ACRODYSOSTOSIS SUPPORT & RESEARCH
Charity registration number	1182818
Principal address	Bath House, Cudworth Lane Newdigate Dorking Surrey SE15 5AF

Trustees

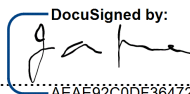
The trustees and officers serving during the year and since the year end were as follows:

Jan Sara Hine
Sarah Louise Denney

Independent examiners

Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
South Tyneside
NE31 2EQ

Approved by the Board of Trustees and signed on its behalf by

DocuSigned by:


.....
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29 October 2021

Jan Sara Hine

ACRODYSOSTOSIS SUPPORT & RESEARCH
Independent Examiners Report to the Trustees
For the year ended 31 December 2020

I report to the trustees on my examination of the accounts of the charitable company for the year ended 31 December 2020.

Responsibilities and basis of report

As the charity Trustees, who are also directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

DocuSigned by:

Garvin Spencer

Beach Accountants Limited

Chartered Certified Accountants

10 Blue Sky Way

Monkton Business Park South

South Tyneside

NE31 2EQ

29 October 2021

ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Activities (including Income and Expenditure Account)
For the year ended 31 December 2020

	Notes	Unrestricted funds £	2019 £
Income and endowments from:			
Donations and legacies	2	89,873	-
Total		<u>89,873</u>	<u>-</u>
Expenditure on:			
Raising funds	3	(3,309)	-
Charitable activities	4/5	(540)	-
Total		<u>(3,849)</u>	<u>-</u>
Net income/expenditure		<u>86,024</u>	<u>-</u>
Total funds carried forward		<u>86,024</u>	<u>-</u>

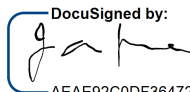
ACRODYSOSTOSIS SUPPORT & RESEARCH
Statement of Financial Position
As at 31 December 2020

	Notes	2020 £	2019 £
Current assets			
Cash at bank and in hand		86,564	-
		86,564	-
Creditors: amounts falling due within one year	10	(540)	-
Net current assets		86,024	-
Total assets less current liabilities		86,024	-
Net assets		86,024	-
The funds of the charity			
Unrestricted income funds	11	86,024	-
Total funds		86,024	-

For the year ended 31 December 2020 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:

DocuSigned by:


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Jan Sara Hine
Trustee

29 October 2021

ACRODYSOSTOSIS SUPPORT & RESEARCH

Notes to the Financial Statements

For the year ended 31 December 2020

1. Accounting Policies**Basis of accounting**

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the Companies Act 2006.

ACRODYSOSTOSIS SUPPORT & RESEARCH meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Going concern

The Trustees have assessed the charities finances and can confirm there is no reason why the charity will not continue to operate for at least 12 months passed the date of approval of these accounts.

2. Income from donations and legacies

	2020	2019
	£	£
Unrestricted funds		
Donations received	89,873	-
	<u>89,873</u>	<u>-</u>

3. Expenditure on generating donations and legacies

	2020	2019
	£	£
Unrestricted funds		
Support costs	3,309	-
	<u>3,309</u>	<u>-</u>

4. Costs of charitable activities by fund type

	2020	2019
	£	£
Unrestricted funds		
Support costs	540	-

5. Costs of charitable activities by activity type

	2020	2019
	£	£
Donation collections	540	-

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2020

6. Analysis of support costs

	2020	2019
	£	£
Governance costs		
Accountancy fees	540	-
Collection fees	2,012	-
Partner fees	1,158	-
Exchange (Profit)/Loss	139	-
	3,849	-

7. Net income/(expenditure) for the year

This is stated after charging/(crediting):

	2020	2019
	£	£
Accountancy fees	540	-
	540	-

8. Staff costs and emoluments

	2020	2019
General staff	0	0
	0	0

9. Trustee remuneration and related party transactions

There were no transactions with trustees or other related parties that required disclosure in this current financial period.

10. Creditors: amounts falling due within one year

	2020	2019
	£	£
Accruals and deferred income	540	-
	540	-

ACRODYSOSTOSIS SUPPORT & RESEARCH
Notes to the Financial Statements Continued
For the year ended 31 December 2020

11. Movement in funds**Unrestricted Funds**

	Incoming resources £	Outgoing resources £	Balance at 31/12/2020 £
<i>General</i>			
General	89,873	(3,849)	86,024
	<u>89,873</u>	<u>(3,849)</u>	<u>86,024</u>

Unrestricted Funds - Previous year

	Incoming resources £	Outgoing resources £	Balance at 31/12/2019 £
<i>General</i>			
	<u>-</u>	<u>-</u>	<u>-</u>

Purpose of unrestricted Funds

General

To fulfil the principal objectives of the charity.

12. Analysis of net assets between funds

	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
General	86,024	86,024
	<u>86,024</u>	<u>86,024</u>

Previous year

	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
	<u>-</u>	<u>-</u>

ACRODYSOSTOSIS SUPPORT & RESEARCH
Detailed Statement of Financial Activities
For the year ended 31 December 2020

	2020	2019
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	89,873	-
	<hr/> 89,873	<hr/> -
Total incoming resources	<hr/> 89,873	<hr/> -
SUPPORT COSTS		
Governance costs		
Governance costs	(3,309)	-
Governance costs	(540)	-
	<hr/> (3,849)	<hr/> -
Total resources expended	<hr/> (3,849)	<hr/> -
Net Income	<hr/> 86,024 <hr/>	<hr/> - <hr/>