

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

Contents Page

For the year ended 31 December 2022

Report of the Trustees	1 to 4
Independent Examiner's Report to the Trustees	5
Statement of Financial Activities	6
Statement of Financial Position	7
Notes to the Financial Statements	8 to 12
Detailed Statement of Financial Activities	13

## ACRODYSOSTOSIS SUPPORT &amp; RESEARCH

## Report of the Trustees

For the year ended 31 December 2022

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 2022. 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 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 &amp; 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**

<b>Name of Charity</b>	ACRODYSOSTOSIS SUPPORT & RESEARCH
<b>Charity registration number</b>	1182818
<b>Principal address</b>	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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Nina Samantha Knight

31 October 2023

**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:

*Gavin Spencer*

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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**

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



## ACRODYSOSTOSIS SUPPORT &amp; RESEARCH

## Statement of Financial Position

As at 31 December 2022

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

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*

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Nina Samantha Knight

Trustee

31 October 2023

## ACRODYSOSTOSIS SUPPORT &amp; 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**

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

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

## ACRODYSOSTOSIS SUPPORT &amp; RESEARCH

## Notes to the Financial Statements Continued

For the year ended 31 December 2022

**4. Analysis of support costs**

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

**5. Net income/(expenditure) for the year**

This is stated after charging/(crediting):

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

**6. Staff costs and emoluments**

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

**7. Trustee remuneration and related party transactions**

The only disclosable transaction 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 &amp; 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 £
<b>Income and endowments from:</b>			
Donations and legacies	8,974	3,417	12,391
<b>Total</b>	<b>8,974</b>	<b>3,417</b>	<b>12,391</b>
<b>Expenditure on:</b>			
Raising funds	(62,659)	-	(62,659)
Charitable activities	(576)	-	(576)
<b>Total</b>	<b>(63,235)</b>	<b>-</b>	<b>(63,235)</b>
<b>Net income/expenditure</b>	<b>(54,261)</b>	<b>3,417</b>	<b>(50,844)</b>
<b>Reconciliation of funds</b>			
Total funds brought forward	86,024	-	86,024
<b>Total funds carried forward</b>	<b>31,763</b>	<b>3,417</b>	<b>35,180</b>

## 9. Creditors: amounts falling due within one year

	2022 £	2021 £
Other creditors	576	-
Accruals and deferred income	576	576
	<b>1,152</b>	<b>576</b>

## 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
	<b>31,680</b>	<b>22,836</b>	<b>(23,284)</b>	<b>31,232</b>

## 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
	<b>86,024</b>	<b>8,974</b>	<b>(63,318)</b>	<b>31,680</b>

## ACRODYSOSTOSIS SUPPORT &amp; 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**

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

**Restricted Funds - Previous year**

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

**Purpose of restricted funds**

## Family Day

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

**11. Analysis of net assets between funds**

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

## ACRODYSOSTOSIS SUPPORT &amp; RESEARCH

## Notes to the Financial Statements Continued

For the year ended 31 December 2022

**Previous year**

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

## ACRODYSOSTOSIS SUPPORT &amp; RESEARCH

## Detailed Statement of Financial Activities

For the year ended 31 December 2022

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