Charity registration number: 1182818

ACRODYSOSTOSIS SUPPORT AND RESEARCH
TRUSTEES' REPORT AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

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

Acrodysostosis Support and research
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Acrodysostosis Support and research
Trustees' Report For The Year Ended 31 December 2025

The trustees present their report and the financial statements for the year ended 31 December 2025.

Objectives and Activities

Aims and Objectives

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.

Public Benefit

The charity’s purpose is to relieve the needs of people affected by acrodysostosis by promoting greater understanding of the causes, symptoms and treatment of the condition. Its work includes supporting and promoting research, sharing research knowledge for the public benefit, and raising awareness of the symptoms, needs and related medical conditions of those living with acrodysostosis.

In planning its work the trustees have regard to the Charity Commission’s public benefit guidance. By sharing information, encouraging family connections, working with researchers and increasing awareness, the charity aims to benefit individuals and families affected by an exceptionally rare genetic condition, as well as the wider public and healthcare community.

Achievements and Performance

Main Achievements

Achievements and performance during 2025

PM Society partnership and Creativity for Good
A defining achievement of 2025 was the charity’s partnership with the PM Society through its Creativity for Good 2024/25 initiative. The programme connected the charity with professional creative expertise and helped bring acrodysostosis to new audiences in healthcare and pharmaceutical communications.

Syneos Health Communications collaborated with the charity on a pro bono basis to develop the #Take5 awareness campaign. The professional time, expertise and creative support donated through the partnership made it possible to deliver an ambitious campaign that would otherwise have been difficult for a small charity to resource.

#Take5: family participation and wider awareness
More than 70 families participated in #Take5, sharing photographs with their hands raised to support awareness of acrodysostosis. The campaign reached thousands of people, helping to amplify the voices of affected families and bring the condition to the attention of people beyond the existing community. These participation and reach measures are based on the charity’s campaign records and estimates.
The campaign illustrated how families, volunteers and professional partners can work together to build visibility and strengthen community engagement around a rare condition.

PM Society Awards and fundraising
On 14 March 2025, Acrodysostosis Support & Research was the charity partner at the 39th PM Society Awards, held at JW Marriott Grosvenor House in London. The event offered an opportunity to explain the charity’s mission and raise funds among an audience of healthcare communications professionals. The event led to considerable funds raised of £12,000. Which was a great achievement.

Ten volunteers helped collect donations at the event. Their energy and willingness to speak to attendees were an essential part of its success.

Two films and a new website

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Main Achievements - continued

Two separate videos were produced in 2025: one by Latterly Ltd in connection with the charity's promotional and awards activities, and a second developed with Syneos Health Communications for #Take5. The charity also launched a new website, giving it an improved platform for communicating its mission, sharing information and connecting with families, professionals and supporters.

Families, peer support and community
The charity continued to place people affected by acrodysostosis at the centre of its work. Family participation in #Take5 was a particular highlight, with more than 70 families helping to raise awareness together. The charity's existing approach to peer support includes connecting families through its community networks and shared information.

Research engagement and medical advice
Supporting understanding of acrodysostosis and encouraging the development of research remain central to the charity's long-term mission. The trustees wish to acknowledge researchers and clinicians working to deepen understanding of the condition and explore possible therapeutic approaches. Particular thanks go to Professor Patrizia Ferretti, Dr Melissa Bowerman, Professor George Baillie and Professor Sue Kimber, alongside the wider scientific and clinical community.
The charity also continued to value the development of a global patient registry as a longer-term priority.

Volunteers, partnerships and special thanks
The charity depends on donated time, skills and goodwill. Hundreds of hours of volunteer and pro bono support were contributed across campaign planning, creative development, fundraising and engagement activities during 2025.

The trustees extend sincere thanks to Jenny Claridge and Dominic Marchant of the PM Society for their encouragement and commitment to the charity partnership, and to the PM Society community for its generosity.

Special thanks also go to Syneos Health Communications and, in particular, Rob Jones, Joe Mills, Ayesha Hussain and Imogen Coupe for their creativity, dedication and substantial contribution to the #Take5 campaign.

The trustees offer heartfelt thanks to Elin Morgan and Karen Dolman for the time and determination they devoted to the campaign alongside the Chair. Both bring an important family perspective to the charity's work.

The trustees thank all ten volunteers who supported collections at the PM Society Awards: Dr Nikita Kanani MBE, Sarah Lamond, Jo O'Connell, Phil Woods, Paul Lopez De Larrinzar, Sharon Forsyth, Dr Chris Ferdinand, Simon Trice, Lucy Lawrie and Nick Brandon.

Particular appreciation is also extended to Kimberley Pykett for designing and making fundraising T-shirts and helping galvanise the AcroD community in support of the campaign. Thanks go to every family who shared a photograph, every donor and supporter, and all those whose voluntary contributions helped the charity achieve so much during the year.

The trustees extend special thanks to Kymie Gleeson for her ongoing commitment to managing the charity's Facebook support group and keeping the AcroD community connected, informed and engaged. Her voluntary contribution helps sustain a welcoming space where affected individuals and families can share experiences and support one another.

The trustees also warmly thank Marcus Latterly for his creative work on the charity's new website and one of its 2025 videos, and for providing these services at a particularly competitive price. His contribution helped the charity strengthen its communications while making careful use of charitable funds.

Order of Women Freemasons – community fundraising
The trustees extend their sincere thanks to the Order of Women Freemasons and its members for raising £409 in support of people affected by acrodysostosis. Particular appreciation is extended to Sharon Betts, Worshipful Master of Lodge St Andrew No. 129, Plymouth, who selected the Acrodysostosis community as her charity of the year from February 2024 to February 2025. Through a Ladies' Gift Evening, garden party, raffles and other fundraising activities, members and supporters generously gave their time and donations. The charity is grateful to Sharon and everyone who participated for their kindness and commitment.

Financial Review

Financial Position

The charity's main sources of funds were public donations and fundraising activity, including donations collected through online payment channels and at the PM Society Awards. The trustees continued to monitor expenditure in support of the charity's objectives, including costs associated with creative materials, digital communications, fundraising equipment, insurance and professional services.

Reserves as of the prior year 2024 were £35,899 and at the end of 2025 in the current year the reserves were £44,569, and overall improvement of £8,670.

Reserves Policy

The trustees seek to maintain sufficient unrestricted reserves to support the charity's ongoing operations and safeguard continuity of its activities, with an aspiration to cover approximately one year of operating costs. The adequacy of reserves is kept under review in light of expected commitments, fundraising opportunities and potential research-related activity.

Reference and Administrative Details

Trustees

Mrs Sarah Denney
Mrs Jan Hine
Miss Nina Knight - Chair

Charity Number

1182818

Principal Address

Bath House
Cudworth Lane
Newdigate, Dorking
Surrey
SE15 5AF

Independent Examiner

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

The trustees' report was approved by the board of trustees and signed on its behalf by:



Miss Nina Knight

Trustee
30/10/2026

Acrodysostosis Support and research
Independent Examiner's Report to the Trustees of Acrodysostosis Support and research
For The Year Ended 31 December 2025

I report to the trustees on my examination of the accounts of Acrodysostosis Support and research (the Trust) for the year ended 31 December 2025.

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 Examiner's 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.

Gavin Spencer

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Beach Accountants Limited ACCA

30/10/2026
10 Blue Sky Way
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Acrodysostosis Support and research
Statement of Financial Activities
For The Year Ended 31 December 2025

	Notes	Unrestricted funds	Restricted funds	2025 Total funds	2024 Total funds
		£	£	£	£
INCOME AND ENDOWMENTS FROM:					
Donations and legacies	**3**	13,122	-	13,122	2,036
EXPENDITURE ON:					
Charitable activities:	**4**				
Governance costs		(278)	-	(278)	(271)
Governance costs (Donation Collection)		(4,174)	-	(4,174)	(1,666)
		(4,452)	-	(4,452)	(1,937)
NET INCOME		8,670	-	8,670	99
NET MOVEMENT IN FUNDS		8,670	-	8,670	99
RECONCILIATION OF FUNDS:					
Total funds brought forward		32,482	3,417	35,899	35,800
TOTAL FUNDS CARRIED FORWARD	**9**	41,152	3,417	44,569	35,899

The notes on pages 9 to 12 form part of these financial statements.

Acrodysostosis Support and research
Comparative Statement of Financial Activities
For The Year Ended 31 December 2025

	Notes	Unrestricted funds	Restricted funds	2024 Total funds
		£	£	£
INCOME AND ENDOWMENTS FROM:				
Donations and legacies	**3**	2,036	-	2,036
EXPENDITURE ON:				
Charitable activities:	**4**			
Governance costs		(271)	-	(271)
Governance costs (Donation Collection)		(1,666)	-	(1,666)
		(1,937)	-	(1,937)
NET INCOME		99	-	99
NET MOVEMENT IN FUNDS		99	-	99
RECONCILIATION OF FUNDS:				
Total funds brought forward		32,383	3,417	35,800
TOTAL FUNDS CARRIED FORWARD	**9**	32,482	3,417	35,899

The notes on pages 9 to 12 form part of these financial statements.

Acrodysostosis Support and research
Statement of Financial Position
As At 31 December 2025

	Notes	Unrestricted funds	Restricted funds	2025 Total funds	2024 Total funds
		£	£	£	£
CURRENT ASSETS					
Debtors	**7**	412	-	412	482
Cash at bank and in hand		47,068	3,417	50,485	40,630
		47,480	3,417	50,897	41,112
Creditors: Amounts Falling Due Within One Year	**8**	(6,328)	-	(6,328)	(5,213)
NET CURRENT ASSETS (LIABILITIES)		41,152	3,417	44,569	35,899
TOTAL ASSETS LESS CURRENT LIABILITIES		41,152	3,417	44,569	35,899
NET ASSETS		41,152	3,417	44,569	35,899
FUNDS OF THE CHARITY					
Restricted Funds				3,417	3,417
Unrestricted Funds				41,152	32,482
TOTAL FUNDS	**9**			44,569	35,899

On behalf of the board

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Miss Nina Knight

Trustee
30/10/2026

The notes on pages 9 to 12 form part of these financial statements.

1. General Information

Acrodysostosis Support and research is a charitable incorporated organisation registered with the Charity Commission, registered charity number 1182818. The principal address is Bath House , Cudworth Lane, Newdigate, Dorking, Surrey, SE15 5AF.

2. Accounting Policies

2.1. Basis of Preparation of Financial Statements

The financial statements have been prepared 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 2019)", Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities Act 2011.

The charity is a Public Benefit Entity as defined by FRS 102.

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

2.2. Going Concern Disclosure

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

2.3. Fund Accounting

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.

2.4. Cash and Cash Equivalents

Cash and cash equivalents are basic financial assets and include cash in hand and deposits held at call with banks, other short-term highly liquid investments that mature in no more than three months from the date of acquisition and are readily convertible to a known amount of cash with insignificant risk of change in value, and bank overdrafts.

2.5. Taxation

The charity is exempt from tax as all its income is charitable and applied for charitable purposes.

2.6.

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 agreedand 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:

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2.6. - continued

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.

3. **Income from Donations and Legacies**

	2025 Unrestricted funds	**2024 Unrestricted funds**
	£	**£**
Donations and gifts	13,122	2,036

4. **Analysis of Expenditure**

	2025 Support costs (see note 5)
	£
Governance costs	278
Governance costs (Donation Collection)	4,174
	4,452

	2024 Support costs (see note 5)
	£
Governance costs	271
Governance costs (Donation Collection)	1,666
	1,937

5. **Support Costs**

	Governance costs	Governance costs (Donation Collection)	2025 Total
	£	£	£
General administration	278	4,174	4,452

	Governance costs	Governance costs (Donation Collection)	2024 Total
	£	£	£
General administration	271	1,666	1,937

6. **Average Number of Employees**

Average number of employees during the year was: NIL (2024: NIL)

7. **Debtors**

	2025	2024
	£	£
Due within one year		
Prepayments and accrued income	412	482

8. **Creditors: Amounts Falling Due Within One Year**

	2025	2024
	£	£
Other creditors	5,518	4,493
Accruals	810	720
	6,328	5,213

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.

9. **Movement in Funds**

	As at 1 January 2025	Income	Expenditure	As at 31 December 2025
	£	£	£	£
Unrestricted funds				
General:				
General unrestricted fund	32,482	13,122	(4,452)	41,152
Restricted funds				
Restricted funds	3,417	-	-	3,417
Total funds	35,899	13,122	(4,452)	44,569

	As at 1 January 2024	Income	Expenditure	As at 31 December 2024
	£	£	£	£
Unrestricted funds				
General:				
General unrestricted fund	32,383	2,036	(1,937)	32,482
Restricted funds				
Restricted funds	3,417	-	-	3,417
Total funds	35,800	2,036	(1,937)	35,899

The resticted funds are for delivering a family day for attendies as prescribed by the donors.

10. **Transactions with Trustees**

None of the trustees received any remuneration or any other benefits from an employment with the charity or a related entity during the current or previous year.

During the financial year the trustee Nina Knight was reminursed for charity costs incurred for subscriptions and insurance
No other trustees were remimbursed for expenses.

	2025	2024
	£	£
Other Expenses	1,025	994

11. **Related Party Disclosures**

There have been no related party transactions in the reporting period that require disclosure, except for those disclosed in the Transactions with Trustees note.

Acrodysostosis Support and research
Detailed Statement of Financial Activities
For The Year Ended 31 December 2025

	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM:		
Donations and legacies		
Donations and gifts	13,122	2,036
	13,122	2,036
	13,122	2,036
EXPENDITURE ON:		
Charitable Activities:		
Governance costs		
Insurance	(278)	(271)
	(278)	(271)
Governance costs (Donation Collection)		
Repairs and maintenances	(366)	-
Advertising and marketing costs	(1,671)	-
Accountancy fees	(882)	(720)
Subscriptions	(1,097)	(946)
Bank charges	(158)	-
	(4,174)	(1,666)
	(4,452)	(1,937)
NET INCOME	8,670	99