

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

Contents Page

For the year ended 31 December 2021

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 & 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
		35,673	86,564
Creditors: amounts falling due within one year	12	(576)	(540)
Net current assets		35,097	86,024
Total assets less current liabilities		35,097	86,024
Net assets		35,097	86,024
The funds of the charity			
Restricted income funds	13	3,417	-
Unrestricted income funds	13	31,680	86,024
Total funds		35,097	86,024

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

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.

ACRODYSOSTOSIS 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	-
	63	-

12. Creditors: amounts falling due within one year

	2021	2020
	£	£
Accruals and deferred income	576	540
	576	540

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
	86,024	8,974	(63,318)	31,680

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
	-	89,873	(3,849)	86,024

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			
<i>General</i>			
General		86,024	86,024
Restricted funds			
		<hr/>	<hr/>
		86,024	86,024
		<hr/>	<hr/>

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