



CHARITY COMMISSION  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From 1<sup>st</sup> April 2024 Period start date to 31<sup>st</sup> March 2025 Period end date

Charity name: Amyloidosis UK

Charity registration number: 1183624

## Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The purposes of the charity (CIO) are the relief of sickness and the preservation and protection of good health among people in the United Kingdom living with the medical condition Amyloidosis.
Summary of the main activities in relation to those purposes for the public benefit the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	<p>During the reporting period, Amyloidosis UK carried out a range of activities in furtherance of its charitable purposes and for the public benefit. The charity's main activities focused on improving information, support and representation for people affected by amyloidosis.</p> <p>The charity provided <b>direct support to beneficiaries</b> through an online support group, a website with a moderated forum, and limited one-to-one support, helping to reduce isolation and improve understanding of the condition among patients and carers. The charity also developed and improved its <b>patient information and communications</b>, ensuring that accurate, accessible information was available to those affected.</p> <p>Last year's rebrand and name change project has significantly increased our visibility and reach, helping us generate substantially more donations to support our work.</p> <p>In addition, the charity undertook <b>advocacy and engagement activity</b> to represent the interests of people with amyloidosis. This included participation in the UK Amyloidosis Network, contributions to NICE and commissioning consultations relating to treatment access, and collaboration with partner organisations on patient insight work, including the Amylife survey. These activities supported informed decision-making within the health system and aimed to improve access to appropriate care and treatment.</p> <p>Trustees have had due regard to the Charity Commission's guidance on public benefit and consider that these activities have delivered clear benefit to people affected by amyloidosis and to the wider health system.</p>



Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The main activities associated with our objectives were formed based on the guidance issued by the Charity Commission on public benefit.
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### Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making.	Para 1.38	N/A
Policy on social investment including program related investment.	Para 1.38	N/A
Contribution made by volunteers.	Para 1.38	Volunteers, including the charity's Trustees, make a significant contribution to Amyloidosis UK. Trustees volunteer their time to provide governance and to support day-to-day activity, while other volunteers contribute lived experience, support engagement and awareness-raising, and help inform consultations and surveys. This voluntary contribution is essential to the charity's ability to operate effectively and deliver public benefit within limited resources.
Other		

## Achievements and Performance

	SORP reference	
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Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society.	Para 1.20	<p>Over the reporting period, the charity made significant progress in strengthening both its external influence and internal capacity, resulting in tangible benefits for people affected by amyloidosis and the wider health system. Through representation on the <b>NHS England Selection Panel for the UK Amyloidosis Network</b>, the charity ensured that patient perspectives helped shape national service development, contributing to more coordinated, equitable care pathways. Our policy and advocacy work—including <b>NICE submissions for Acordamis and Vutrisiran</b> and engagement with the <b>NHS Wales Joint Commissioning Committee consultation on Tafamidis</b>—has amplified the patient voice in decision-making around access to life-changing treatments, with the potential to improve outcomes and quality of life for current and future patients.</p> <p>Awareness-raising remained a priority, with the charity attending the <b>Labour Party Conference</b> to increase understanding of amyloidosis among policymakers, helping to address its status as a rare and often overlooked condition. Direct support for beneficiaries was strengthened through the launch of an <b>online support group</b>, reducing isolation and providing peer connection and shared understanding for people living with amyloidosis and their families.</p> <p>Alongside this, the charity invested in internal development to ensure sustainability and effectiveness. The development of a <b>communications strategy and website improvements</b> have enhanced the clarity, accessibility and reach of information for patients, carers and professionals. Finally, the <b>Amylife survey</b>, delivered in collaboration with the Amyloidosis Alliance, generated valuable patient-reported insights, that we will use to identify unmet needs and inform future service improvement, research priorities and advocacy. Collectively, this work has improved patient support, strengthened system-level decision-making, and contributed to wider societal benefits through better awareness, evidence-informed policy, and more responsive healthcare for rare disease communities.</p>
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#### Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set.	Para 1.41	N/A
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Performance of fundraising activities against objectives set.	Para 1.41	N/A
Investment performance against objectives	Para 1.41	N/A
Other		

## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Cash at bank at 31/3/2025 was £73866.46 in unrestricted funds.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	N/A
Number of reserves held	Para 1.22	N/A
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	N/A

### Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	Our main source of funds this year has been grants and donations.
Investment policy and objectives including any social investment policy adopted.	Para 1.46	As a small charity we do not have this.
A description of the principal risks facing the charity.	Para 1.46	NONE



## Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (Trust deed, royal charter)	Para 1.25	(Foundation model constitution)
How is the charity constituted? (e.g., unincorporated association, CIO)	Para 1.25	Charitable Incorporated Organisation (CIO)
Trustee selection methods including details of any constitutional provisions e.g., election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	This forms part of the governing document. New trustees are selected by current trustees.

### Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees.	Para 1.51	Forms part of the Foundation' model constitution.
The charity's organisational structure and any wider network with which the charity works.	Para 1.51	<p>The charity is governed by a <b>Board of seven Trustees</b>, who hold overall responsibility for strategy, governance, compliance and financial oversight. Due to the charity's small size, Trustees also take an <b>active role in the day-to-day running of the charity</b>, alongside their governance responsibilities. Operational activity is supported by a <b>freelance charity coordinator</b>, who assists with delivery, administration and communications under the direction of the Trustees.</p> <p>The charity works closely with a range of <b>external partners</b> to maximise its impact. These include <b>NHS England</b>, through involvement in the UK Amyloidosis Network, <b>NICE</b> and devolved nation commissioning bodies, specialist clinicians and treatment centres, and other patient and rare disease organisations, including the <b>Amyloidosis Alliance</b>. The charity also engages with policy stakeholders and supports peer connection through its <b>online support group</b>, ensuring that beneficiary voices inform decision-making and service development.</p>
Relationship with any related parties	Para 1.51	N/A

Other		

## Reference and Administrative details

Charity name	Amyloidosis UK
Other name the charity uses	N/A
Registered charity number	1183624
Charity's principal address	Office 7, First Floor, No 11 Riverside Industrial Park Farnham GU9 7UG



## Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for full year	Name of person (or body) entitled to appoint trustee (if any)
1	Paul Pozzo	Chairman		
2	Vincent Nicholas	Treasurer		
3	David Gregory	Secretary		
4	Ruth Bramwell	Trustee		
5	Carlos Heras - Palou	Trustee		
6	Ben Laryea	Trustee		
7	Julian Macleod	Trustee		
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Corporate trustees – names of the directors at the date the report was approved.

Director name		
N/A		

Name of trustees holding title to property belonging to the charity.

Trustee name	Dates acted if not for full year	
N/A		

Funds held as custodian trustees on behalf of others.

Description of the assets held in this capacity.	
	N/A

Name and objects of the charity on whose behalf the assets are held and how these falls within the custodian charity's objects.	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

### Additional information (optional)

#### Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
N/A		

#### Name of chief executive or names of senior staff members (Optional information)

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### Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A
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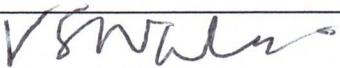
### Other optional information

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### Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Vincent Nicholas	
Position (e.g., Secretary, Chair, etc)	Treasurer	
Date	28th January 2026	



Amyloidosis UK

**INCOME SUMMARY**

**YEAR ENDING:**

31/03/2025

DATE	CUSTOMER	£
02/04/2024	Paypal	£57.06
05/04/2024	LH Perspective	£200.00
23/04/2024	Donation	£1,000.00
29/04/2024	Just Giving	£33.73
20/04/2024	Eidos Therapeutics	£14,988.00
28/05/2024	Just Giving	£731.63
03/06/2024	Just Giving	£561.79
25/06/2024	Unum European Hold	£30.00
25/06/2024	Astrazenecha	£15,000.00
01/07/2024	Just Giving	£43.56
08/07/2024	Just Giving	£63.56
10/07/2024	Paypal	£359.25
29/07/2024	Just Giving	£4.70
02/08/2024	Intellia Therapeutic	£17,600.00
03/09/24	Just Giving	£4.70
13/09/24	Donation	£68.55
01/10/24	Just Giving	£33.73
02/10/24	CG Benevity	£100.00
09/10/24	Donation	£90.00
15/10/24	Much Loved	£98.84
21/10/24	Just Giving	£90.14
04/11/24	Just Giving	£273.48
15/11/24	Much Loved	£555.08
26/11/24	Just Giving	£900.41
02/12/24	Paypal	£185.08
05/12/24	Alnylam UK	£15,000.00
11/12/24	Just Giving	£4,938.43
16/12/24	Much Loved	£500.97
16/12/24	Just Giving	£115.61
23/12/24	Just Giving	£204.80
30/12/24	CG Benevity	£310.00
06/01/25	Donatis	£18.74
07/01/25	Just Giving	£10,400.92
15/01/25	Much Loved	£1,589.31
20/01/25	Just Giving	£77.57
22/01/25	Donation	£100.00
27/01/25	Just Giving	£302.90
04/02/25	Donation	£162.87
11/02/25	Donation	£195.00
17/02/25	Much Loved	£793.14
17/02/25	Just Giving	£1,172.77
20/02/25	Just Giving	£180.58
24/02/25	Memory Giving	£207.01
25/02/25	Donatis	£141.45
25/02/25	Memory Giving	£47.04
03/03/25	Just Giving	£1,179.39
06/03/25	Exafield	£40.00

[illegible]



Top income streams

JUST GIVING	23955.57
Eidos Therapeutics	22488
Intellia Therapeutic	17600
Astrazenecha	15400
Alnylam UK	15000
Much Loved	3853.04
Belvedere Trust	3000
Donation	1616.42
PAYPAL	945.17
CG Benevity	410
Memory Giving	329.32
CAF	200
LH Perspective	200
Donatis	160.19
Exafield	40
Unum European Hold	30

105227.7

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DATE	SUPPLIER	Details	Total	SUBSCRIPTIONS	TRAVEL ACCOMODATION & SUBSISTENCE (CONFERENCES)	WAGES, SALARIES AND STAFF COSTS	RENT, RATES, POWER & INSURANCE	ENTERTAINMENT	CONSULTANCY	ACCOUNTANCY, LEGAL & PROFESSIONAL COSTS	PAYMENT FOR TRIALS	TELEPHONE, FAX, STATIONERY AND OTHER OFFICE COSTS	ADVERTISING/ WEBSITE/Exhibi tions	BANK, CREDIT CARD CHARGES	OTHER BUSINESS EXPENSES	CAPITAL PURCHASES (OVER £200)
05/04/2024	Seth Mowshowitz	30	121.5										121.5			
05/04/2024	Seth Mowshowitz	31	120										120			
06/04/2024	Bank Charges		5											5		
16/04/2024	Paul Pozzo	BHF	477.53		363.53								114			
16/04/2024	Seth Mowshowitz	32	333.81										333.81			
16/04/2024	Seth Mowshowitz	33	226.38										226.38			
16/04/2024	Seth Mowshowitz	34	310										310			
23/04/2024	Mr C Heras-Palou	Madrid	725.65		725.65											
01/05/2024	Another Planet	1904613	619.95										619.95			
01/05/2024	Kate Taylor	45	1483.2			1483.2										
01/05/2024	Kate Taylor	46	1580.4			1580.4										
01/05/2024	Kate Taylor	47	1306			1306										
01/05/2024	Kate Taylor	48	686.44			686.44										
07/05/2024	Bank Charges		5											5		
08/05/2024	Paul Pozzo	BSH	448.94		409.45							39.49				
20/05/2024	RBC		6											6		
24/05/2024	Ben Laryea	BSH	99.92		99.92											
24/05/2024	David Gregory	Alnylam	146.78		146.78											
24/05/2024	Seth Mowshowitz	35	300										300			
24/05/2024	VG Nichols	Alnylam	64.35		64.35											
06/06/2024	Bank Charges		5											5		
13/06/2024	Paul Pozzo	Alnylam	70.24		60.3							9.94				
26/06/2024	Balbir Bains	intellia	150								150				0	
26/06/2024	Paul Pozzo	Intellia	150								150					
26/06/2024	Peter Lusby	intellia	150								150					
26/06/2024	Ruane	intellia	150								150					
08/07/2024	Bank Charges		5											5		
10/07/2024	Zurich		9.6				9.6									
19/07/2024	Paul Pozzo	Lab Conf Hotel	1311.7		1311.7											
26/07/2024	Another Planet	1904669	2655.63										2655.63			
29/07/2024	Seth Mowshowitz	36	350										350			
02/08/2024	RBC		6											6		
06/08/2024	Bank Charges		5											5		
06/08/2024	Kate Taylor	51	1290.24			1290.24										
06/08/2024	Kate Taylor	50	1169.28			1169.28										
06/08/2024	Kate Taylor	49	1612.8			1612.8										
12/08/2024	David Gregory	Zoom	178	178												
12/08/2024	Zurich		9.6				9.6									
21/08/2024	R & N Kent	2504	775				775									
06/09/2024	Bank Charges		5											5		
06/09/2024	Thirusha Lane	001	585						585							
10/09/2024	Zurich		9.6				9.6									
18/09/2024	Kate Taylor	51	1008			1008										
18/09/2024	Kate Taylor	Laptop	1404.7	76.7												1328
25/09/2024	Seth Mowshowitz	37	115.51										115.51			
29/09/2024	Everso	13709	159.6										159.6			
01/10/2024	R & N Kent	2552	275				275									
03/10/2024	Seth Mowshowitz	38	140.52										140.52			

07/10/2024	Bank Charges		5										5			
10/10/2024	Zurich		9.6			9.6										
11/10/2024	Seth Mowshowitz	39	640									640				
15/10/2024	Thirusha Lane	002	540					540								
26/10/2024	Kate Taylor	53	1229.76		1229.76											
26/10/2024	Paul Pozzo	Lab Conf	796.19											796.19		
29/10/2024	David Gregory	NAC	433.87		433.87											
29/10/2024	R & N Kent	2573	275			275										
05/11/2024	BSH	AM2024012	1740									1740				
05/11/2024	BSH	BSHQ2024026	1663.44									1663.44				
05/11/2024	VG Nichols	NAC	129.92		129.92											
06/11/2024	Bank Charges		5.8										5.8			
13/11/2024	Zurich		9.6			9.6										
15/11/2024	Thirusha Lane	003	720					720								
29/11/2024	ICO		35						35							
02/12/2024	R & N Kent	2594	275			275										
02/12/2024	Seth Mowshowitz		1160									1160				
07/12/2024	Bank Charges		5										5			
10/12/2024	Zurich		9.6			9.6										
13/12/2024	Kate Taylor	54	1693.44		1693.44											
13/12/2024	Kate Taylor	55	1451.52		1451.52											
13/12/2024	Medipace	0075	2644.5									2644.5				
13/12/2024	Thirusha Lane	004	1064					1064								
02/01/2025	Paul Pozzo	BSH/NAC	333.63		333.63											
02/01/2025	R & N Kent	2616	275			275										
06/01/2025	Bank Charges		5										5			
10/01/2025	Zurich		9.6			9.6										
17/01/2025	Kate Taylor	56	846		846											
17/01/2025	Thirusha Lane	Dec	700					700								
30/01/2025	Sally Williams	42	150						150							
03/02/2025	Astraea HR	1253	432						432							
03/02/2025	R & N Kent	2634	275			275										
06/02/2025	Bank Charges		5										5			
09/02/2025	Et Al	006	1064					1064								
09/02/2025	Kate Taylor	57	936		936											
09/02/2025	Seth Mowshowitz	44	500									500				
09/02/2025	Zesty	281	4315.2									4315.2				
10/02/2025	Zurich		9.6			9.6										
25/02/2025	Just Giving	Subs	18	18												
03/03/2025	Kate Taylor	Exp	124.59		124.59											
03/03/2025	R & N Kent	2652	275			275										
07/03/2025	BSH Services	25-06	690									690				
07/03/2025	Kate Taylor	58	1608		1608											
07/03/2025	Seth Mowshowitz	48	420									420				
07/03/2025	VG Nichols	Farnham meet	479.6			479.6										
09/03/2025	Bank Charges		6.2										6.2			
10/03/2025	Zurich		9.6			9.6										
12/03/2025	David Gregory	Farnham meet	286.3		286.3											
12/03/2025	RBC		6										6			
18/03/2025	Et Al	007	588					588								
25/03/2025	Just Giving		18	18												
28/03/2025	Ben Laryea	Farnham meet	23		23											
28/03/2025	Noelyn Mae	Exp	46.05		46.05											
			0													
			0													
			53813.48	290.7	4559.04	17901.08	2511.4	479.6	5261	617	600	49.43	19340.04	80	796.19	1328



**Amyloidosis UK**  
**INCOME & EXPENDITURE ACCOUNT**  
**YEAR ENDING:**

31/03/2025

**INCOME**

SALES	105,228
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**EXPENDITURE**

SUBSCRIPTIONS	291
TRAVEL ACCOMODATION & SUBSISTENCE (CONFERENCES)	4,559
WAGES, SALARIES AND STAFF COSTS	17,901
RENT, RATES, POWER & INSURANCE	2,511
ENTERTAINMENT	480
CONSULTANCY	5,261
ACCOUNTANCY, LEGAL & PROFESSIONAL COSTS	617
PAYMENT FOR TRIALS	600
TELEPHONE, FAX, STATIONERY AND OTHER OFFICE COSTS	49
ADVERTISING/WEBSITE/Exhibitions	19,340
BANK, CREDIT CARD CHARGES	80
OTHER BUSINESS EXPENSES	796

-52,485

PROFIT/LOSS IN YEAR	52,742
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**Amyloidosis UK**  
**BALANCE SHEET ITEMS**

CAPITAL PURCHASES (OVER £200)	1,328
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Amyloidosis UK

**YEAR ENDING:**

31/03/2025

Opening Balance	22452.23
Purchases	53813.48
Sales/Donations	105227.7
End Balance	73866.46

Bank Balance as per bank statement at 31/03/25	73866.46
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Difference	0
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Section A

Independent Examiner's Report

Report to the trustees

Charity Name  
AMYLOIDOSIS UK

On accounts for the year  
ended

31/03/25

Charity no  
(if any)

1183624

Set out on pages

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2025**

Responsibilities and basis  
of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent examiner's statement** I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination (other than that disclosed below \*) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.

\* Please delete the words in the brackets if they do not apply.

Signed: Sally Williams

Date: 18  
/01/2026

Name: SALLY WILLIAMS

Relevant professional  
qualification(s) or body  
(if any):



**Address:** 11 THE FAIRWAY, FARNHAM, GU9 9BB

## Section B

### Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details of any items that the examiner wishes to disclose.**