

# Amyloidosis UK

England & Wales · Charity number 1183624

## Details

---

**Other names** UK ATTR AMYLOIDOSIS PATIENTS' ASSOCIATION (UKATPA)

**Status** Registered

**Legal form** CIO

**Registered** 2019-05-29

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

## Contact

---

**Address** Office 7  
First Floor  
No 11  
Riverside Industrial Park  
Farnham  
GU9 7UG

**Phone** 07881914013

**Email** [info@amyloidosisuk.org](mailto:info@amyloidosisuk.org)

**Website** [www.amyloidosisuk.org](http://www.amyloidosisuk.org)

## Activities

---

**Objects:** THE OBJECTS OF THE 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 ATTR AMYLOIDOSIS (KNOWN AS THE 'CONDITION') IN PARTICULAR BUT NOT EXCLUSIVELY BY:A) PROVIDING INFORMATION, SUPPORT AND ADVICE TO PEOPLE LIVING WITH THE CONDITION, THEIR FAMILIES AND CARERS;B) ADVOCATING TO ENSURE THAT EVERY PERSON HAS TIMELY AND EFFECTIVE DIAGNOSIS, TREATMENT AND CARE OF THE CONDITION;C) WORKING CLOSELY WITH ALL STAKEHOLDERS TO FACILITATE THE AVAILABILITY OF EFFECTIVE TREATMENTS FOR THE CONDITION.D) FUNDING AND SUPPORTING RESEARCH TO ADVANCE SCIENTIFIC UNDERSTANDING OF THE CONDITION AND ITS EFFECTIVE TREATMENT AND TO PUBLISH THE USEFUL RESULTS THEREOF FOR THE PUBLIC BENEFIT.

**Activities:** a) providing information, support and advice to people living with the Condition, their families and carers; b) advocating to ensure that every person has timely and effective diagnosis, treatment and care of the Condition;c) working closely with all stakeholders to facilitate the availability of effective treatments for the Condition. d) funding and supporting research to advance scientific

## Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives

## Geography

- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£105,228	£53,813	-	-
2024-03-31	£1,533	£18,297	-	-
2023-03-31	£3,700	£16,431	-	-
2022-03-31	£33,000	£31,000	-	-
2021-03-31	£31,258	£9,625	-	-

## Trustees

Name	Role	Appointed
CARLOS HERAS-PALOU		2018-12-01
David Gregory		2019-09-27
Julian Robert Macleod		2025-02-20
Paul Pozzo		2020-10-19
Ruth Eleanor Bramwell		2018-12-01
Vincent Graham Nesan Nicholas		2018-12-01

**Amyloidosis UK**

England & Wales - Charity number 1183624

---

# Accounts

---



## 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.
--	-----------	--

**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	
--	----------------	--

<p>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.</p>	<p>Para 1.20</p>	<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>
---	------------------	--

**Additional information (optional)**

You may choose to include further statements where relevant about:

<p>Achievements against objectives set.</p>	<p>Para 1.41</p>	<p>N/A</p>
---	------------------	------------

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 external partners 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)**

--

**Exemptions from disclosure**

Reason for non-disclosure of key personnel details

N/A
-----

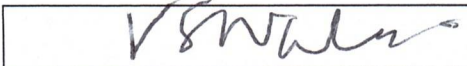
**Other optional information**

--

**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



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

/



EXPENDITURE DETAIL

YEAR ENDING:

31/03/2025

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/Exhibitions	BANK, CREDIT CARD CHARGES	OTHER BUSINESS EXPENSES	CAPITAL PURCHASES (OVER £200)
05/04/2024	Seth Mowshowitz		30										121.5			
05/04/2024	Seth Mowshowitz		31										120			
06/04/2024	Bank Charges													5		
16/04/2024	Paul Pozzo	BHF			363.53								114			
16/04/2024	Seth Mowshowitz		32										333.81			
16/04/2024	Seth Mowshowitz												226.38			
16/04/2024	Seth Mowshowitz												310			
23/04/2024	Mr C Heras-Palou	Madrid			725.65											
01/05/2024	Another Planet	1904613											619.95			
01/05/2024	Kate Taylor	45				1483.2										
01/05/2024	Kate Taylor	46				1580.4										
01/05/2024	Kate Taylor	47				1306										
01/05/2024	Kate Taylor	48				686.44										
07/05/2024	Bank Charges													5		
08/05/2024	Paul Pozzo	BSH			409.45							39.49				
20/05/2024	RBC													6		
24/05/2024	Ben Laryea	BSH			99.92											
24/05/2024	David Gregory	Alnylam			146.78											
24/05/2024	Seth Mowshowitz												300			
24/05/2024	VG Nichols	Alnylam			64.35											
06/06/2024	Bank Charges													5		
13/06/2024	Paul Pozzo	Alnylam			60.3											
26/06/2024	Balbir Bains	intellia									150	9.94			0	
26/06/2024	Paul Pozzo	Intellia									150					
26/06/2024	Peter Lusby	intellia									150					
26/06/2024	Ruane	intellia									150					
08/07/2024	Bank Charges													5		
10/07/2024	Zurich						9.6									
19/07/2024	Paul Pozzo	Lab Conf Hotel			1311.7											
26/07/2024	Another Planet	1904669											2655.63			
29/07/2024	Seth Mowshowitz												350			
02/08/2024	RBC													6		
06/08/2024	Bank Charges													5		
06/08/2024	Kate Taylor	51				1290.24										
06/08/2024	Kate Taylor	50				1169.28										
06/08/2024	Kate Taylor	49				1612.8										
12/08/2024	David Gregory	Zoom		178												
12/08/2024	Zurich						9.6									
21/08/2024	R & N Kent	2504					775									
06/09/2024	Bank Charges													5		
06/09/2024	Thirusa Lane	001							585							
10/09/2024	Zurich						9.6									
18/09/2024	Kate Taylor	51				1008										
18/09/2024	Kate Taylor	Laptop		76.7												1328
25/09/2024	Seth Mowshowitz												115.51			
29/09/2024	Everso	13709											159.6			
01/10/2024	R & N Kent	2552					275									
03/10/2024	Seth Mowshowitz												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	Thirusa 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	Thirusa 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	Thirusa 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	Thirusa 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

**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
--	----------

Difference	0
------------	---



**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.**

--

**Amyloidosis UK**

England & Wales - Charity number 1183624

---

# Accounts

---



**Trustees' Annual Report for the period**

**From 1<sup>st</sup> April 2023 Period start date to 31<sup>st</sup> March 2024 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	In planning our activities for the year, we kept in mind the Charities objectives and the Charity Commission's guidance on public benefit. Our objective is: a) providing information, support and advice to people living with the Condition, their families, and carers. b) advocating to ensure that every person has timely and effective diagnosis, treatment, and care of the Condition. c) working closely with all stakeholders to facilitate the availability of effective treatment and care for the Condition. d) supporting research to advance scientific understanding of the Condition and its effective treatment and to publish the useful results thereof for the public benefit.
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.

**Additional information (optional)**

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making.	Para 1.38	N/A
	Para 1.38	N/A

Policy on social investment including program related investment.		
Contribution made by volunteers.	Para 1.38	All trustees are volunteers.
Other		

## Achievements and Performance

	SORP reference	
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	<ul style="list-style-type: none"> <li>We developed a theory of change, a mission and vision for our organisation to give us clear direction and aims.</li> <li>We developed and launched our first strategy, setting out a clear direction and priorities for the future.</li> <li>We applied for grant funding to cover the cost of delivering the first phase of our strategy.</li> <li>We changed our name and rolled out new branding to increase our recognition and visibility and as part of our strategy.</li> </ul> <p>This work mean that more patients will be able to find us and seek our support. More patients will be able to find our website and get the information they need. As the only Amyloidosis specific charity in the UK, we aim to create a supportive community, increasing our visibility in the community is vital to us delivering on this aim.</p> <p>We, also:</p> <ul style="list-style-type: none"> <li>Represented the patient voice as two new medications passed through the NICE and SMC approval processes. Both medications were approved for use in Scotland and England. For some groups of patients, this means they have access to disease altering treatments for the first time ever.</li> <li>Attended several professional conferences and events to promote our work and increase awareness of the disease.</li> </ul>

		This benefits patients by increasing awareness among health care professionals.
--	--	---

### Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set.	Para 1.41	N/A
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 31/3/2024 was £22452.23 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
Other		

## 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	We have six trustees and an administrator: Chairman Treasurer Secretary Trustee Trustee Trustee We do not belong to a wider network.
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	Hackamore House, Grove Lane, Redlynch, Salisbury SP5 2NR.

**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				
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)**

--

**Exemptions from disclosure**

Reason for non-disclosure of key personnel details

N/A
-----

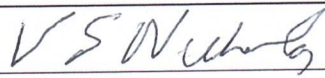
**Other optional information**

--

**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 2025



		<b>£1,532.97</b>

JUST GIVING	354.45
CG Benevity	5
CHEQUES	112.5
CHARITABLE GIVING	137.78
Donation	150
Pfizer	214
PAYPAL	259.24
ONLINE GIVING	
GKA INSENTIVE	300

1532.97



**UK ATTR Amyloidosis Patients Association (AKATPA)**

**INCOME & EXPENDITURE ACCOUNT**

**YEAR ENDING:**

31/03/2024

**INCOME**

SALES 1533

**EXPENDITURE**

SUBSCRIPTIONS 258

TRAVEL ACCOMODATION & SUBSISTENCE (CONFERENCES) 5064

WAGES, SALARIES AND STAFF COSTS 8205

RENT, RATES, POWER & INSURANCE 96

DONATIONS

ACCOUNTANCY, LEGAL & PROFESSIONAL COSTS 165

INTEREST ON BANK AND OTHER LOANS

TELEPHONE, FAX, STATIONERY AND OTHER OFFICE COSTS 63

ADVERTISING/WEBSITE/Exhibitions 4386

BANK, CREDIT CARD CHARGES 61

OTHER BUSINESS EXPENSES

---

-18297

PROFIT/LOSS IN YEAR -16764

**UK ATTR Amyloidosis Patients Association (AKATPA)**

**BALANCE SHEET ITEMS**

CAPITAL PURCHASES (OVER £200)

**UK ATTR Amyloidosis Patients Association (AKATPA)**

**YEAR ENDING:** 31/03/2024

Opening Balance	39216.69
Purchases	18297.43
Sales/Donations	1532.97
End Balance	22452.23

Bank Balance as per bank statement at 31/03/23	22452.23
--	----------

Difference	7.276E-12
------------	-----------

**Amyloidosis UK**

England & Wales - Charity number 1183624

---

# Accounts

---



## Trustees' Annual Report for the period

From 1<sup>st</sup> April 2022 Period start date to 31<sup>st</sup> March 2023 Period end date

Charity name: UK ATTR Amyloidosis Patients' Association (UKATPA)

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 ATTR 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	In planning our activities for the year, we kept in mind the Charities objectives and the Charity Commission's guidance on public benefit. Our objective is: a) providing information, support and advice to people living with the Condition, their families, and carers. b) advocating to ensure that every person has timely and effective diagnosis, treatment, and care of the Condition. c) working closely with all stakeholders to facilitate the availability of effective treatments for the Condition. d) funding and supporting research to advance scientific understanding of the Condition and its effective treatment and to publish the useful results thereof for the public benefit.
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.

### 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	All trustees are volunteers.
Other		

## Achievements and Performance

	SORP reference	
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>With the continued relaxation of Covid restrictions this year we were able to explore more face-to-face activities. Below is a breakdown of all the main achievements:</p> <ul style="list-style-type: none"> <li>• We have continued our outreach work with the Afro-Caribbean community.</li> <li>• Continued to support patients in the UK and beyond with information, one to one support etc.</li> <li>• Attended conferences to raise awareness of Amyloidosis and UKATPA among key professional groups (BSHF etc).</li> <li>• Helped improve patient access to treatments by representing the patient's voice during the NICE assessment process. Two new drugs approved during this period.</li> <li>• Appointed a new chair of trustees at the end of the financial year.</li> <li>• Created a Scientific Advisory Group to guide our work in the future.</li> <li>• Initiated projects to improve our visibility and reach so we can help more patients.</li> <li>• Initiated support for carers of patients with Amyloidosis.</li> </ul>

### Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set.	Para 1.41	N/A
--------------------------------------	-----------	-----

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 31/3/2023 was £39,216.69. 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	In the first part of the year, it was the restrictions that COVID-19 had presented.

## 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	We have six trustees and an administrator: Chairman Treasurer Secretary Trustee Trustee Trustee We do not belong to a wider network.
Relationship with any related parties	Para 1.51	N/A
Other		

### Reference and Administrative details

Charity name	UK ATTR Amyloidosis Patients' Association (UKATPA)
Other name the charity uses	N/A
Registered charity number	1183624
Charity's principal address	Hackamore House, Grove Lane, Redlynch, Salisbury SP5 2NR.

**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	Carlos Heras - Palou	Chairman		
2	Vincent Nicholas	Treasurer		
3	David Gregory	Secretary		
4	Ruth Bramwell	Trustee		
5	Paul Pozzo	Trustee		
6	Ben Laryea	Trustee		
7				
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)**

--

**Exemptions from disclosure**

Reason for non-disclosure of key personnel details

N/A
-----

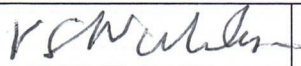
**Other optional information**

--

**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	5th January 2024



## Receipts and payments accounts

CC16a

For the period from	01/04/22	To	31/03/23
---------------------	----------	----	----------

### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
JUST GIVING	58	-	-	58	-
LESLEY SILK	200	-	-	200	-
CHEQUES	1,447	-	-	1,447	-
CHARITABLE GIVING	166	-	-	166	-
FIECON LTD	1,098	-	-	1,098	-
BARRY BRADLEY	350	-	-	350	-
PAYPAL	92	-	-	92	-
ONLINE GIVING	189	-	-	189	-
GKA INSENTIVE	100	-	-	100	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>3,700</b>	<b>-</b>	<b>-</b>	<b>3,700</b>	<b>-</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>3,700</b>	<b>-</b>	<b>-</b>	<b>3,700</b>	<b>-</b>
<b>A3 Payments</b>					
MEMBERSHIP FEES	43	-	-	43	-
TRAVEL ACCOMODATION & SUBSISTENCE (CONFERENCES)	5,753	-	-	5,753	-
WAGES, SALARIES AND STAFF COSTS	4,234	-	-	4,234	-
RENT, RATES, POWER & INSURANCE	-	-	-	-	-
DONATIONS	79	-	-	79	-
ACCOUNTANCY, LEGAL & PROFESSIONAL COSTS	155	-	-	155	-
INTEREST ON BANK AND OTHER LOANS	62	-	-	62	-
TELEPHONE, FAX, STATIONERY AND OTHER OFFICE COSTS	86	-	-	86	-
ADVERTISING/WEBSITE	6,019	-	-	6,019	-
<b>Sub total</b>	<b>16,431</b>	<b>-</b>	<b>-</b>	<b>16,431</b>	<b>-</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>16,431</b>	<b>-</b>	<b>-</b>	<b>16,431</b>	<b>-</b>
<b>Net of receipts/(payments)</b>	<b>- 12,731</b>	<b>-</b>	<b>-</b>	<b>- 12,731</b>	<b>-</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>- 12,731</b>	<b>-</b>	<b>-</b>	<b>- 12,731</b>	<b>-</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>		-	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	-	-	-
	(agree balances with receipts and payments account(s))	Agreement Error	OK	OK
<b>B2 Other monetary assets</b>	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B5 Liabilities</b>	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
		-	-	-
		-	-	-
		-	-	-
		-	-	-
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	

**Amyloidosis UK**

England & Wales - Charity number 1183624

---

# Accounts

---



## Trustees' Annual Report for the period

From 1<sup>st</sup> April 2021 Period start date to 31<sup>st</sup> March 2022 Period end date

Charity name: UK ATTR Amyloidosis Patients' Association (UKATPA)

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 ATTR 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	In planning our activities for the year, we kept in mind the Charities objectives and the Charity Commission's guidance on public benefit. Our objective is: <ul style="list-style-type: none"> <li>a) providing information, support and advice to people living with the Condition, their families, and carers.</li> <li>b) advocating to ensure that every person has timely and effective diagnosis, treatment, and care of the Condition.</li> <li>c) working closely with all stakeholders to facilitate the availability of effective treatments for the Condition.</li> <li>d) funding and supporting research to advance scientific understanding of the Condition and its effective treatment and to publish the useful results thereof for the public benefit.</li> </ul>
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.

### 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	All trustees are volunteers.
Other		

## Achievements and Performance

	SORP reference	
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>With the relaxation of Covid restrictions this year we were able to explore more face-to-face activities. Below is a breakdown of all the main achievements:</p> <ul style="list-style-type: none"> <li>• We secured funding for and delivered a new website offering information and advice for anyone with an interest in ATTR Amyloidosis. It is more patient, and family focused than our original website.</li> <li>• We have continued our outreach work with the Afro-Caribbean community.</li> <li>• In partnership with other organisations (Pharma and NHS) we have delivered the 'One Step Further' campaign which is a combination of videos and support material that is on our website and booklets to support patients and carers.</li> <li>• Developed a 5-year strategy to help the organisation grow and deliver high quality services.</li> <li>• Worked to develop a network of interested professionals and patients.</li> <li>• Attended conferences to raise awareness of Amyloidosis and UKATPA among key professional groups (BHF etc).</li> </ul>

### Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set.	Para 1.41	N/A
--------------------------------------	-----------	-----

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 31/3/2022 was £51.9K 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	The main risk to the charity is the restrictions that COVID-19 has presented.

Other		


### Financial Review

<p>Review of the entity's financial condition at the end of the period.</p>	<p>Review of the entity's financial condition at the end of the period.</p>
<p>Statement of the entity's policy for holding reserves.</p>	<p>Statement of the entity's policy for holding reserves.</p>
<p>Review of the entity's financial condition at the end of the period.</p>	<p>Review of the entity's financial condition at the end of the period.</p>
<p>Review of the entity's financial condition at the end of the period.</p>	<p>Review of the entity's financial condition at the end of the period.</p>
<p>Review of the entity's financial condition at the end of the period.</p>	<p>Review of the entity's financial condition at the end of the period.</p>

<p>Additional information (optional): You may choose to include further statements when relevant about the financial condition of funds for the year has been granted and approved.</p>	<p>Additional information (optional): You may choose to include further statements when relevant about the financial condition of funds for the year has been granted and approved.</p>
---	---

<p>As a result of this review, we have the following policy and objectives for the year's social investment policy adopted.</p>	<p>As a result of this review, we have the following policy and objectives for the year's social investment policy adopted.</p>
<p>The financial condition of the entity is the financial condition that COVID-19 has presented.</p>	<p>The financial condition of the entity is the financial condition that COVID-19 has presented.</p>

## 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	We have five trustees: Chairman Treasurer Secretary Trustee Trustee We do not belong to a wider network.
Relationship with any related parties	Para 1.51	N/A
Other		

### Reference and Administrative details

Charity name	UK ATTR Amyloidosis Patients' Association (UKATPA)
Other name the charity uses	N/A
Registered charity number	1183624
Charity's principal address	The Old Parsonage, Hyde Lane, Hartington. SK17 0AP

**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	Carlos Heras - Palou	Chairman		
2	Vincent Nicholas	Treasurer		
3	David Gregory	Secretary		
4	Ruth Bramwell	Trustee		
5	Paul Pozzo	Trustee		
6				
7				
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)**

--

**Exemptions from disclosure**

Reason for non-disclosure of key personnel details

N/A
-----

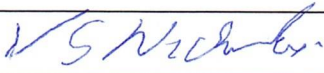
**Other optional information**

--

**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	10 <sup>th</sup> January 2023	







**UK ATTR Amyloidosis Patients Association (AKATPA)**

**INCOME & EXPENDITURE ACCOUNT**

**YEAR ENDING:**

31/03/2022

**INCOME**

SALES 32679

**EXPENDITURE**

TRAINING 165

CAR, VAN AND TRAVEL EXPENSES 2892

WAGES, SALARIES AND STAFF COSTS 4196

RENT, RATES, POWER & INSURANCE

DONATIONS 3200

ACCOUNTANCY, LEGAL & PROFESSIONAL COSTS 135

INTEREST ON BANK AND OTHER LOANS

TELEPHONE, FAX, STATIONERY AND OTHER OFFICE COSTS 106

ADVERTISING/WEBSITE 20220

BANK, CREDIT CARD CHARGES 15

OTHER BUSINESS EXPENSES

-----  
-30928

PROFIT/LOSS IN YEAR 1751

**UK ATTR Amyloidosis Patients Association (AKATPA)**

**BALANCE SHEET ITEMS**

CAPITAL PURCHASES (OVER £200)

**UK ATTR Amyloidosis Patients Association (AKATPA)**

**YEAR ENDING:** 31/03/2022

Opening Balance	50197.09
Purchases	30928.46
Sales/Donations	32679.12
End Balance	51947.75

Bank Balance as per bank statement at 31/03/21	51947.75
--	----------

Difference



CHARITY COMMISSION  
FOR ENGLAND AND WALES

### Independent examiner's report on the accounts

**Section A** Independent Examiner's Report

Report to the trustees/  
members of

On accounts for the year ended  Charity no (if any)

Set out on pages

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2022.

**Responsibilities and basis of report** As the charity trustees of the Trust, 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 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 (other than that disclosed below \*) in connection with the examination which gives me cause to believe that in any material respect:

- 1\* accounting records were not kept in accordance with section 130 of the Act or
- 2\* the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn 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:  Date:

Name:

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

Address:

**Amyloidosis UK**

England & Wales - Charity number 1183624

---

# Accounts

---



## Trustees' Annual Report for the period

From 1<sup>st</sup> April 2020 Period start date to 31<sup>st</sup> March 2021 Period end date

Charity name: UK ATTR Amyloidosis Patients' Association (UKATPA)

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 ATTR 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	In planning our activities for the year, we kept in mind the Charities objectives and the Charity Commission's guidance on public benefit. Our objective is: <ul style="list-style-type: none"> <li>a) providing information, support and advice to people living with the Condition, their families, and carers.</li> <li>b) advocating to ensure that every person has timely and effective diagnosis, treatment, and care of the Condition.</li> <li>c) working closely with all stakeholders to facilitate the availability of effective treatments for the Condition.</li> <li>d) funding and supporting research to advance scientific understanding of the Condition and its effective treatment and to publish the useful results thereof for the public benefit.</li> </ul>
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.

### 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	All trustees are volunteers.
Other		

## Achievements and Performance

	SORP reference	
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>Due to Covid this year has taken a different route than expected. Instead of organising UK regional Information Days we held them via zoom. We were able to organise medical talks and reached more patients and their carers using zoom. We also took part with other Amyloidosis groups worldwide on their zoom support meetings.</p> <p>We were also invited again by NICE to be Patient Experts on the evaluation panel for new Amyloidosis drug to represent the patient voice. We have been heavily involved in supporting and taking part in Amyloidosis surveys organised by the Pharma companies and hospitals.</p> <p>In February we started a series of joint projects with the National Amyloidosis Centre in London and Pharma company to make awareness of the importance of early diagnoses of the disease. We have started the Afro-Caribbean Community outreach and disease awareness campaign.</p>

### Additional information (optional)

You may choose to include further statements where relevant about:

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

Investment performance against objectives	Para 1.41	
Other		

## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Cash at bank at 31/3/2021 was £50.19K 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	The main risk to the charity is the restrictions that COVID-19 has presented.
Other		

## 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	We have five trustees: Chairman Treasurer Secretary Trustee Trustee We do not belong to a wider network.
Relationship with any related parties	Para 1.51	N/A
Other		

### Reference and Administrative details

Charity name	UK ATTR Amyloidosis Patients' Association (UKATPA)
Other name the charity uses	N/A
Registered charity number	1183624
Charity's principal address	The Old Parsonage, Hyde Lane, Hartington. SK17 0AP

**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	Carlos Heras - Palou	Chairman		
2	Vincent Nicholas	Treasurer		
3	David Gregory	Secretary		
4	Ruth Bramwell	Trustee		
5	Paul Pozzo	Trustee		
6				
7				
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)**

--

**Exemptions from disclosure**

Reason for non-disclosure of key personnel details

N/A
-----

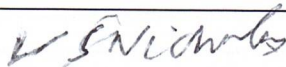
**Other optional information**

--

**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	1 <sup>st</sup> November 2021	







**UK ATTR Amyloidosis Patients Association (UKATPA)  
INCOME & EXPENDITURE ACCOUNT**

**YEAR ENDING:**

###

**INCOME**

SALES 31258

**EXPENDITURE**

GOODS & MATERIALS

CAR, VAN AND TRAVEL EXPENSES 142

WAGES, SALARIES AND STAFF COSTS 1023

RENT, RATES, POWER & INSURANCE

REPAIRS AND RENEWALS OF PROPERTY & EQUIPMEN

ACCOUNTANCY, LEGAL & PROFESSIONAL COSTS 135

INTEREST ON BANK AND OTHER LOANS

TELEPHONE, FAX, STATIONERY AND OTHER OFFICE C 144

ADVERTISING 8147

BANK, CREDIT CARD CHARGES 34

OTHER BUSINESS EXPENSES

-----  
-9625

PROFIT/LOSS IN YEAR 21633

**UK ATTR Amyloidosis Patients Association (UKATPA)  
BALANCE SHEET ITEMS**

CAPITAL PURCHASES (OVER £200)

**UK ATTR Amyloidosis Patients Association (AKATPA)**

**YEAR ENDING:           ###**

Opening Balance	28564
Purchases	9624.71
Sales/Donations	31258
End Balance	50197

Bank Balance as per bank statement at 31/03/21	50197
--	-------

Difference



# Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/ members of

UK ATTR Amyloidosis Patients' Association (UKATPA)

On accounts for the year ended

31/03/21

Charity  
no (if any)

1183624

Set out on pages

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2021.

Responsibilities and basis of report

As the charity trustees of the Trust, 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 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 (other than that disclosed below \*) in connection with the examination which gives me cause to believe that in, any material respect:

- 1\* accounting records were not kept in accordance with section 130 of the Act or
- 2\* the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn 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:

Date:

11/10/21

Name:

Sally Williams

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

Address:

11 The Fairway, Farnham, Surrey GU9 9BB