



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day 01	Month 04	Year 24		Day 31	Month 03	Year 25

Section A Reference and administration details

Charity name Amy and Friends

Other names charity is known by

Registered charity number (if any) 1119746

Charity's principal address

OCC	
Village Road	
Oxton	
Postcode	CH43 5SR

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Roy McGunigall	Chairman		
2	Mark Hughes	Treasurer		
3	Shaun Fanning			
4	Jodie Barden			
5	Phillipa Sellar			
6				
7				
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17				
18				
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20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

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

Jayne Hughes

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	Association
Trustee selection methods (eg. appointed by, elected by)	Elected by existing trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

For the relief of people suffering with Cockayne Syndrome, TTD and related disorders and the preservation and protection of the good health of the families and carers of such persons.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Annual Members Retreat:

This is Amy and Friends main activity. Amy and Friends organise a 3 day retreat over a weekend for children and young people affected by Cockayne Syndrome, their parents, brothers, sisters or carers. Families have the opportunity to spend time in each other's company and to share experiences and support one another. During the retreat every opportunity to have fun is fully taken through organisation of a party, children's entertainment and a family excursion and sibling activities. It is an opportunity to relax, to not feel isolated in a loving, caring environment.

Annual Medical/Scientific Conference:

Amy and Friends arrange for leading doctors and researchers from around the world to attend a scientific conference and present research progress and seek opportunities to collaborate as well as offer additional advice or guidance to families and to further their own knowledge about these exceptionally rare disorders.

CS/TTD Clinic Support:

A CS/TTD clinic has been established at St Thomas and Guys Hospital (London) for multidisciplinary meetings for sufferers. Amy and friends makes referrals to clinic for its members and coordinates family support during each clinic. The clinics have increased from monthly to twice per month.

Advice and Guidance:

Advice and guidance are offered continually. This is through events as mentioned above and through regular phone and email contact and through Amy and Friends secure web forum. Amy and Friends also keep close contact with medical practitioners and researchers in order to direct families to specialist knowledge as appropriate.

Advocacy:

Amy and Friends continually work to further knowledge about Cockayne Syndrome with Health professionals, politicians and policy makers and the general community. This has been achieved through regular media coverage, community events and conference organisation. We are also actively supporting research into the disease.

Family Support Workers:

Amy and Friends provides a family support worker who assists in hospital visits, medical support and advice and guidance for families etc.

All planned activities are considered against the Charity commission guidance on public benefit.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Summary of the main achievements of the charity during the year

- Support/Advocacy
 - Conference: 52 sufferers, 68 families (223 family members (Parents and siblings) attended), 32 scientists, 49 volunteers – Venue (Blackpool)
 - Approved Leaflets with FAQ's e.g. nutrition
 - 62 x Family Support Home Visits, Sibling trip (4 days Camping), Mum's day
 - Monthly Online Wellbeing sessions for adult male carers
 - Weekly Online sibling activity sessions
 - Bereavement and anticipatory grief support service provided for all family members/carers
- Scientific/Medical
 - UK Clinic increased to 2x per month: 73 patients/ 65 families seen
 - Numerous scientific papers published and a number recognising A&F support
 - Biopharm 4x engagers
 - Attended 7 scientific networking events
- People
 - Management skills Training
 - Safeguarding policy updated and trained out
 - First aid training including paediatric and specialist choking
 - 49 active volunteers (Increased from 40)
 - Jayne Hughes (CEO) recognised with British Empire medal for services to children with rare disorders
 - BBC Carer of the year award
 - Merseyside woman of the years: Woman of courage award
- Fundraising
 - Increase in funds raised mainly due to a very active private individuals fundraising support.

Section E

Financial review

Brief statement of the charity's policy on reserves

If fundraising target was exceeded in a financial year by £5000, a reserve account would be established and 50% of any such amount would be placed in this account, the other 50% to be available for use by the organisation for the development of new services.

Details of any funds materially in deficit

N/A

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Section F

Other optional information

Section G

Declaration

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

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Mark Hughes

Position (eg Secretary, Chair, etc)

Treasurer

Date

08/1/2026



AMY AND FRIENDS

INDEPENDENT EXAMINER'S REPORT ON THE ACCOUNTS

FOR THE YEAR ENDED 31 MARCH 2025

CHARITY REGISTERED NUMBER: 1119746



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

Amy and Friends

On accounts for the year ended

31 March 2025

Charity no
(if any)

1119746

Set out on pages

2 and 3

I report to the trustees on my examination of the accounts of the above charity for the year ended 31 March 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 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.

Signed:

Date: 31.10.25

Name: Daniel Hicks

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

FCA Fellow Chartered Accountant

Address:

Unit 11, Mold Business Park

Wrexham Road

Mold, CH7 1XP



**CHARITY COMMISSION
FOR ENGLAND AND WALES**

Amy and Friends

1119746

CC16a

Receipts and payments account

For the period from	Period start date	to	Period end date
	01 April 2024		31 March 2025

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 £
A1 Receipts					
Just giving/paypal/donations	166,445	-	-	166,445	78,485
Children in Need	-	-	-	-	-
Fund Raising events & activities	-	-	-	-	24,813
Morgan Foundation	-	29,167	-	29,167	22,917
Main grants	-	168,968	-	168,968	56,576
Global MSN	-	-	-	-	700
COVID	-	-	-	-	-
Bank interest	-	-	-	-	-
Small grants	37,033	-	-	37,033	58,530
The Will Charitable Trust	-	15,000	-	15,000	20,000
Interest	395	-	-	395	442
Sub total (Gross income for AR)	203,873	213,134	-	417,007	262,462
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	203,873	213,134	-	417,007	262,462
A3 Payments					
International conference etc	73,491	9,634	-	83,125	35,552
Garage rent	-	-	-	-	1,472
Clinic & Gifts for Children	65	40,104	-	40,169	32,776
MTTBM (Sibling's Club)	-	-	-	-	-
Salaries and pensions	14,697	58,786	-	73,483	82,040
Fundraising & just giving	92,223	-	-	92,223	13,196
Scientific conferences	-	5,348	-	5,348	-
Family support	-	58,408	-	58,408	37,033
Travel	-	-	-	-	2,127
Stationery & office	1,909	1,909	-	3,818	1,017
Computer & website costs	4,577	4,577	-	9,154	6,730
Office Expenses	-	-	-	-	-
Accountancy	618	618	-	1,237	9
Telephone	1,352	1,352	-	2,705	2,574
Professional costs	1,679	1,679	-	3,357	2,829
Subscriptions	110	110	-	221	-
Training	-	-	-	-	1,610
Other expenses	-	-	-	-	14,897
Purchases	-	-	-	-	-
Bank charges	-	-	-	-	-
Sundry expenses	-	-	-	-	-
Volunteer expenses	163	163	-	-	-
Insurance	555	555	-	1,109	1,024
Sub total	191,439	183,242	-	374,357	234,886
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	191,439	183,242	-	374,357	234,886
Net of receipts/(payments)	12,435	29,892	-	42,327	27,576
A5 Transfers between funds					
A6 Cash funds last year end	13,969	67,503	-	81,472	53,896
Cash funds this year end	26,404	97,395	-	123,799	81,472



CHARITY COMMISSION
FOR ENGLAND AND WALES

Amy and Friends

1119746

CC16a
(cont.)

Statement of assets and liabilities

For the period

to

31 March 2025

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 £
B1 Cash funds	Lloyds TSB Current Account Lloyds Treasurers Account Grant money rec'd in advance Total cash funds	44,904 - 18,500 26,404	81,555 35,840 - 20,000 97,395	
	0	0	0	
B2 Other monetary assets				
B3 Investment assets				
B4 Assets retained for the charity's own use				
B5 Liabilities				
Signed by one or two trustees (on behalf of all the trustees)		Print Name		
		M. HUGHES		5/11/25



AMY AND FRIENDS

INDEPENDENT EXAMINER'S REPORT ON THE ACCOUNTS

FOR THE YEAR ENDED 31 MARCH 2025

CHARITY REGISTERED NUMBER: 1119746



CHARITY COMMISSION
FOR ENGLAND AND WALES

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Global MSN	-	-	-	-	700
COVID	-	-	-	-	-
Bank interest	-	-	-	-	-
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CHARITY COMMISSION
FOR ENGLAND AND WALES

Amy and Friends

1119746

CC16a
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Statement of assets and liabilities

For the period

to

31 March 2025

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