



# Trustees' Annual Report for the period

<b>From</b>	Period start date			<b>To</b>	Period end date		
	Day 01	Month 04	Year 20		Day 31	Month 03	Year 21

## 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	
<b>Postcode</b>	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	Jackie Newsham	Secretary		
4	Victoria Jenkins		16/12/19	Vote by Trustees
5	Spencer Jenkins			
6	Shaun Fanning			
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
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. Amy and Friends arrange for leading doctors and researchers to attend to offer additional advice or guidance and to further their own knowledge about this exceptionally rare disorder. 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.

#### **My time to be me:**

A weekly club held in 3 locations (Wallasey and Rhyl and Flint) for siblings affected by living with a sibling with a life limiting illness or has a immediate family member that has died or will die prematurely.

#### **CS Clinic Support:**

A monthly 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.

#### **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. Amy and Friends has also developed a relationship with Thomas and Guys Hospital which is going to lead to the formation of a multi-disciplinary CS clinic run in conjunction with our support group.

#### **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**

The 2021 conference was held at St David Hotel, Ewloe and access provided virtually using ZOOM. 52 families attended in person and a further 20 attended via ZOOM.

Now supporting in excess of 1300 families in total.

Amy and Friends has been able to engage families from the Asian community within the UK and offer support and guidance.

Additional Family support worker (Funded position) dedicated to support of families at the CS/TTD clinic and throughout the year.

Additional Family support worker engaged specifically for Welsh Families (Funded position)

Held a virtual International medical/scientific conference in the UK with 24 participants. 7 attended personally.

Credited as contributors on published medical journal articles.

During Covid:

1. Zoom meetings taking place each week and how much of welcome these have been - mums talk/dads talk and siblings groups, these have been a huge success and will continue through 2021.
2. Over 20,000 activity packs have been sent to families who have a child with a severely life affecting illness/issue since the end of March 2020. These packs have been sent UK wide. Funding from various organisations has meant that children who are isolated have received materials and ideas with instructions (printed and sent via video link).



## 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

15/12/2021



**AMY AND FRIENDS**

**INDEPENDENT EXAMINER'S REPORT ON THE ACCOUNTS**

**FOR THE YEAR ENDED 31 MARCH 2021**

**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

31/03/2021

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 2021.

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:

DG Hicks

Date:

16-Sep-21

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 2020		31 March 2021

### 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/paypal/donations	19,958	4,226	-	24,183	47,270
Children in Need	-	6,250	-	6,250	23,750
Fund Raising events & activities	5,136	-	-	5,136	19,902
Morgan Foundation	-	17,120	-	17,120	6,893
Main grants	-	55,822	-	55,822	28,824
Covid grants	-	118,845	-	118,845	-
Bank interest	-	-	-	-	7
Small grants	16,887	329	-	17,216	36,597
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>41,981</b>	<b>202,592</b>	<b>-</b>	<b>244,572</b>	<b>163,243</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>41,981</b>	<b>202,592</b>	<b>-</b>	<b>244,572</b>	<b>163,243</b>
<b>A3 Payments</b>					
International conference etc	19,686	4,226	-	23,912	49,654
Garage rent	-	-	-	-	1,300
Clinic & Gifts for Children	631	-	-	631	19,606
MTTBM (Sibling's Club)	-	-	-	-	16,601
Salaries and pensions	13,903	79,193	-	93,095	58,860
Fundraising & just giving	1,182	-	-	1,182	2,222
Covid care packs	-	115,116	-	115,116	3,553
Travel	482	-	-	482	78
Stationery & office	932	-	-	932	-
Computer & website costs	1,257	-	-	1,257	777
Office Expenses	-	-	-	-	-
Accountancy	1,260	-	-	1,260	2,419
Telephone	3,194	-	-	3,194	2,772
Professional costs	1,680	-	-	1,680	2,010
Subscriptions	99	-	-	99	736
Training	33	-	-	33	-
Other expenses	-	-	-	-	-
Purchases	2,548	329	-	2,877	5,625
Bank charges	-	-	-	-	25
Sundry expenses	-	-	-	-	-
Insurance	835	-	-	835	769
	-	-	-	-	-
<b>Sub total</b>	<b>47,720</b>	<b>198,863</b>	<b>-</b>	<b>246,583</b>	<b>167,007</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>47,720</b>	<b>198,863</b>	<b>-</b>	<b>246,583</b>	<b>167,007</b>
<b>Net of receipts/(payments)</b>	<b>- 5,740</b>	<b>3,729</b>	<b>-</b>	<b>- 2,011</b>	<b>- 3,764</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>43,446</b>	<b>-</b>	<b>-</b>	<b>43,446</b>	<b>47,210</b>
<b>Cash funds this year end</b>	<b>37,706</b>	<b>3,729</b>	<b>-</b>	<b>41,435</b>	<b>43,446</b>





CHARITY COMMISSION  
FOR ENGLAND AND WALES

Amy and Friends

1119746

CC16a  
(cont.)

# Statement of assets and liabilities

For the period

to

31 March 2021

## 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>	Lloyds TSB Current Account Lloyds Treasurers Account Covid Support grant received in advance <b>Total cash funds</b>	27,704 10,002 - <b>37,706</b>	14,354 - 10,625 <b>3,729</b>	- - - -
<b>B2 Other monetary assets</b>	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<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)
	Office equipment/computers	Unrestricted	4,996	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<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	
		M. HUGHES	5/10/21	



**AMY AND FRIENDS**

**INDEPENDENT EXAMINER'S REPORT ON THE ACCOUNTS**

**FOR THE YEAR ENDED 31 MARCH 2021**

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For the period

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Signed by one or two trustees (on behalf of all the trustees)	Signature	Print Name	Date of approval	
		M. HUGHES	5/10/21	