



RAISING AWARENESS & FUNDS
IN SUPPORT OF CLINICAL RESEARCH
FOR SPINAL MUSCULAR ATROPHY (SMA)

Registered Charity 1201716

Trustees Report and Accounts Year ended 24th January 2025

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1. Structure, governance and management

Charity name	RALLY ROUND RUPERT
Charity Registration	Registered in England and Wales; Number 1201716
Contact Address	81 Jennings Road, St Albans, AL1 4NY
Bank	Natwest Bank, St Albans
Trustees	George Mosey (Chairperson) Charlotte Mosey Janet Harvey Matthew Atkinson Annemari Merilainen-Ottridge (appointed 11th December 2024) Paul Drayton (appointed 11th December 2024) Dave Auckland (appointed 11th December 2024)
Website and Social Media	www.rallyroundrupert.org.uk https://www.instagram.com/rallyroundrupert/ https://www.youtube.com/@RallyRoundRupertCharity
Contact us	info@rallyroundrupert.org.uk

2. Report of the Trustees for the Year Ended 24 January 2025

The Trustees, who also serve as directors of Rally Round Rupert (hereafter referred to as "the Charity") for the purposes of the Companies Act 2006, are pleased to present their Annual Report and Unaudited Financial Statements for the year ended 24 January 2025.

a. Charitable Purpose Statement:

The objectives and aims of the Charity are to relieve the need and protect the health of children and their families affected by Spinal Muscular Atrophy (SMA) throughout England & Wales for the public benefit by:

- Working to improve the understanding and knowledge of Spinal Muscular Atrophy (SMA) among the public.
- Providing financial support to further advance clinical research into Spinal Muscular Atrophy (SMA).

b. Fundraising Activities and Performance in the Year

The Trustees are pleased to report on the Charity's activities and financial performance for the year ended 24 January 2025.

The Charity's primary objective is to generate income in support of its charitable purpose. This is typically achieved through a flagship annual fundraising event, supplemented by smaller, standalone activities throughout the year. These efforts are supported by an ongoing strategy to raise awareness of SMA via the Charity's website and social media platforms.

In June 2024, the Charity hosted its major fundraising event — '100 WALK 100' — a 100-mile charity walk along the Cotswold Way. The event, held over three days, attracted more than 100 participants and was a resounding success both in terms of fundraising and engagement.

The event proved to be a tremendous success, generating over £110,000 in direct donations for the Charity. Beyond these essential funds, the event significantly raised public awareness of the condition, garnering widespread media coverage across local radio and newspapers.

During the year, the Charity also launched a new website, serving as a central hub for media content and providing regular updates on how donated funds are being utilised - Rallyroundrupert.org.uk

The charity also continues to raise awareness through its Instagram page, which now has over 29,000 followers.

Start of event - Chipping Camden



End of event – Bath Cathedral



c. Charitable Activities – Clinical Research

During the year, the charity pledged £107,000 of funds to Great Ormond Street Hospital and partners, to conduct a 2-year Nutritional study. This study has successfully commenced, and results are expected to be published in 2026/27.



Funding of £100,000 has been awarded to the University of Oxford to fund a clinical trial into physiotherapy for children with SMA.



d. Future outlook

Following a successful year of fundraising, the Charity is planning to support an additional clinical research initiative in 2025. Ongoing discussions with Sheffield Children's Hospital are focused on a proposed study entitled 'SMA Spinal Management Study'. Further details, including the overall cost of the project, are expected to become clearer as these discussions progress later in the year.

The Board of Trustees remains firmly committed to deepening the understanding of Spinal Muscular Atrophy (SMA) and advancing clinical research in this vital area.

On behalf of the Trustees, we would like to say a sincere thank you to all our supporters and volunteers, individuals who have given their time and money so generously and wholeheartedly. We would not be where we are without your help, and we very much appreciate it.

3. Financial Review and Governance

a) Financial Review

The Charity raises funds to meet its objectives while maintaining financial stability. In its second year since registering as a charity, Rally Round Rupert had net expenditure of £39,582 (2024 - net income £183,074). This arose from £132,187 of income from fundraising events (2024 - £188,798), partially offset by the costs of raising funds of £9,752 (2024 - 5,724) and supported by interest income £3,379 (2024 - nil). The charity undertook charitable activities in the year totalling £165,396 (2024 - nil) which was constituted of supporting clinical research projects with major internationally recognised research organisations.

As at 24 January 2024, the Charity had total net assets of £143,492 (2024 - £183,074) of which £41,604 is designated for the ongoing support of the SMA4Nutrition project. All of the income for the year is unrestricted. The Charity has adequate reserves to continue in operation and support its ongoing obligations as they fall due.

b) Governance

The charity is controlled by its governing document and a deed of trust and operates as a Charitable Incorporated Organisation (CIO). There is an annual review of trustees in line with the governing documents of the Charity.

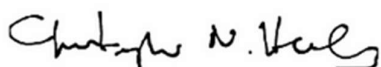
Following a review of capability and capacity of the existing structure during the year, the charity recruited three additional trustees. This was to diversify the trustees' skill set, add resource, and to enable the charity to continue to develop and deliver its objectives.

c) Independent Examiner's Report

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do 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.



Christopher Hardy ACA
Associate of The Institute of Chartered Accountants in England & Wales
4 Hambleden Drive
Wallingford
OX10 0PQ
Date: 12th June 2025

Approved by order of the board of trustees on 12th June 2025 and signed on its behalf by:



George Alec Mosey – Trustee and Chairperson of Rally Round Rupert
12th June 2025

4. Accounts

Statement of financial activities For the year ended 24 January 2025

Notes		Year ended 24th January 2025	Year ended 24th January 2024
		Unrestricted fund £	Unrestricted fund £
	Income		
2	Other trading activities	132,187	188,798
	Total income	132,187	188,798
	Expenditure		
6	Expenditure on raising funds	(9,752)	(5,724)
7	Expenditure on charitable activities	(165,396)	0
	Total expenditure	(175,148)	(5,724)
3	Interest Income	3,379	0
	Net income / (expenditure)	(39,582)	183,074
	Net movement in funds	(39,582)	183,074
	Total funds brought forward	183,074	0
	Total funds carried forward	143,492	183,074

Balance Sheet As at 24 January 2025

Notes		24th January 2025	24th January 2024
		£	£
9	Prepayments	2,395	0
	Cash at bank and in hand	145,997	183,074
	Total current assets	148,392	183,074
10	Creditors: amounts falling due within one year	(4,900)	0
	Net current assets/(liabilities)	143,492	183,074
	Total net assets	143,492	183,074
	General fund	101,888	73,074
	Designated fund	41,604	110,000
8	Total Funds	143,492	183,074

Notes to the financial statements
For the year ended 24 January 2025

Accounting Policies

1 Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2022. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that economic benefits will flow to the charity and if the amount can be measured reliably.

Expenditure

Expenditure is the amount of the charity's resources that have been spent or otherwise used up in carrying out its activities. Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Taxation

The charity is exempt from tax on its charitable activities given all income is used for charitable purposes.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees for either general use or designated for a particular use.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Cash at bank and in hand

Cash at bank and in hand is held to meet short term cash commitments as they fall due and includes all cash equivalents held in the form of short term highly liquid investments. A cash equivalent will have a maximum maturity date of three months from the date of acquisition.

Reserves Policy

The Trustees have adopted the following reserves policy to ensure the ongoing operational stability of the charity and its ability to meet its strategic objectives.

The Trustees aim to hold a minimum operational reserve of £10,000 in cash. This is to provide a cushion against unexpected drops in income or unforeseen costs.

Beyond this operational reserve, the charity's model is to accumulate general unrestricted funds ahead of awarding research grants. The Trustees will identify and plan for future expenditures, and this will inform the overall level of funds held. The Trustees acknowledge that following a significant disbursement on charitable activities, reserves may fall but commitments will not be made that take the position below the minimum operational reserve level.

At 24 January 2025, the charity's reserves of £143,492 are above the target minimum operational reserve. The Trustees consider this level adequate to continue in operation, support ongoing obligations, and begin accumulating funds for the next cycle of research projects.

Investment Policy

The trustees will only place cash with banks with a Moody's rating of AA3 or better. The trustees will place cash in an interest bearing deposit account to the extent that it is not required in the short term to optimise investment income.

2 Other trading activities

Other trading activities comprises entirely of income from fundraising events.

3 Investment Income

Investment income relates to bank interest received during the year.

4 Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year end 24th January 2025 (2024 - Nil)

5 Trustees' expenses

There were no trustees' expenses paid for by the charity for the year ended 24th January 2025 (2024 - Nil)

6 Expenditure on raising funds

Expenditure on raising funds relates to costs associated with a fundraising event.

	Year to 24th January 2025	Year to 24th January 2024
	£	£
Event material cost	4,858	312
Website costs	339	26
Other administrative costs	187	
GoFundMe transaction costs	4,368	5,385
Total expenditure on raising funds	9,752	5,724

7 Expenditure on charitable activities

	Year to 24th January 2025	Year to 24th January 2024
	£	£
SMA 4Nutrition	65,396	-
ACE SMA Physio Trial	100,000	-
Total charitable activity costs	165,396	-

8 Movement in funds

	At 25th January 2024 £	Net movement in funds £	At 24th January 2025 £	
Unrestricted funds				
General fund	73,074	28,814	101,888	
Designated	110,000	(68,396)	41,604	
Total funds	183,074	(39,582)	143,492	
	Incoming resources £	Utilised in the year £	Transfer between funds £	Movement in funds £
Unrestricted funds				
General fund	125,814	(100,000)	3,000	28,814
Designated		(65,396)	(3,000)	(68,396)
Total funds	125,814	(165,396) -	-	(39,582)

The General Fund represents the free reserves of the charity available for its general charitable purposes.

The Designated Fund of £110,000 brought forward from 2024 was designated for research into the nutritional needs of children with SMA. £65,396 was utilised for this purpose leaving further amounts committed of £41,604 that will be paid during 2025. The remaining £3,000 was transferred to general funds during the year ended 24 January 2025.

Amounts from the General Fund (£100,000) and Designated Fund (£65,396) totalling £165,396 were applied to fund the Expenditure on Charitable Activities (see Note 7).

The "Incoming resources" of £125,814 allocated to the General Fund in the detailed movement note above, plus the £9,752 expenditure on raising funds, and the £3,379 interest income, combined with the charitable expenditure allocation make up the overall financial activity reflected in the SOFA.

9 Prepayments

	As at 24th January 2025	As at 24th January 2024
Prepaid expenses for fundraising event	2,395	-
Total	2,395	-

10 Creditors

	As at 24th January 2025	As at 24th January 2024
Deferred income	4,900	-
Total	4,900	-

11 Related party disclosures

There were no related party transactions with any of the trustees for the year ended 24 January

12 Events after the reporting period

There were no events after the end of the reporting period affecting the charity.

13 Independent examiner cost

The services provided by the independent examiner were carried out gratuitously and no fees were incurred.