



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

Registered Charity 1201716

Trustees Report & Accounts
Year ended 24 January 2024

Rally Round Rupert

Contents

1. Officers, advisers, and contact details
2. A personal message from the Chairperson
3. Our Mission
 - Charitable purpose statement
 - Public benefit
 - Beneficiaries
4. Operational
 - Structure, Governance and Management
 - Trustee appointment
5. Financial review
 - Introduction and overview
 - Future outlook
 - Financial position
 - Independent examiners report
 - Statement of financial activities
 - Balance sheet
 - Notes to the financial statements

The Trustees present their annual report along with the accounts covering the twelve months ended 24 January 2024. The accounts have been prepared based on the accounting policies set out in note 1 of the financial statements and comply with the charity's constitution.

Rally Round Rupert

1. Officers, advisers, and contact details

| | |
|--------------------------|--|
| Charity name | RALLY ROUND RUPERT |
| Charity registration | Registered in England and Wales; number 1201716 |
| Trustees | <p>The current Trustees are:</p> <p>George Mosey (Chairperson)</p> <p>Charlotte Mosey Janet Harvey (All appointed 25 January 2023)</p> <p>Matthew Atkinson (Appointed 26 May 2023)</p> |
| Bank | <p>NATWEST</p> <p>St Albans (A) Branch, 10 St Peter's Street, St Albans, Herts, AL1 3LY</p> |
| Independent examiner | Christopher Hardy ACA |
| Website and social media | <p>Rally Round Rupert website @rallyroundrupert</p> |
| Contact us | <p>Rally Round Rupert website rallyroundrupert@outlook.com</p> |
| Contact address | 81 Jennings Road, St Albans, AL1 4NY |
| Donate to help us | GoFundMe |

Rally Round Rupert

2. A personal message from the Chairperson

It's been over a year since we launched Rally Round Rupert and it's incredible to reflect on how far we have come in such a short space of time. I can speak on behalf of all the Trustees when I say how proud we are of the charity's progress. Specifically, how much awareness of the condition we have managed to raise, while also generating over £183,000, vital funds which will now directly support clinical research.

Our charity walk in June 2023, **'100 WALK 100 - The Cleveland Way'**, was the main feature of the year, a resounding success that brought together a huge community of committed and engaged volunteers, as well over 100 participants. The event also attracted a huge amount of local media attention and the support of several high-profile [celebrities](#), further helping to promote the condition and the charity itself. I would like to thank everyone that helped to make the three days such a success, in particular the dedicated team of volunteers who made possible all the logistics, catering, and marshalling. Without your help we would not have been able to safely guide and support over 100 people, over 100 miles, a sincere thank you to you all.

Following the event, the funds we have generated can now be put toward much needed clinical research, providing immediate liquidity to projects awaiting funding or in the mobilisation phase.

In the first instance, Rally Round Rupert has been working closely with three institutions; Great Ormond Street Hospital (GOSH), Sapre-Uonpia (Italy) and the International Centre for the Assessment of Nutritional Studies (ICANS) at the University of Milan. In July 2024, we intend to fully fund a 2-year piece of clinical research, which aims to investigate the nutritional status, body composition, energy expenditure and dietary habits of infants and children with SMA types I and II, who have been treated with the available therapeutic options. The research's secondary aim is to evaluate the role of body composition and energy metabolism of fat free mass (kcal/kg), as biomarkers to predict responses of patients receiving disease-modifying treatments. This essential research will help better inform clinicians around SMA and nutrition, thus improving long term patient wellbeing.

Rally Round Rupert also intends to part fund a piece of clinical research, led by Oxford University, which aims to review optimised rehabilitation programmes for treated patients with SMA, comparing these to the current rehabilitation programmes in the United Kingdom. Again, this is a much-anticipated piece of research that will add to the existing body of knowledge, while also helping to consolidate thinking amongst clinicians, leading to more effective and consistent care plans for patients.

These two pieces of clinical research are extremely important to the SMA community and would not have been possible without funding from the charitable sector. The intention is that they will not only lead to better levels of clinical care, but also sponsor a broader level of clinical coordination and leadership, themes that our charity holds dear.

Within the year, Rally Round Rupert has also launched a new [website](#), which will serve as a central point of reference and contact, allowing the charity to host its latest information. Going forward, we will be signposting volunteers and potential donors to this page, helping to ensure that there is consistency of messaging and a single location where we can explain about the clinical research we are supporting. Secondly, next year we are also looking to expand the number of Trustees within the charity, ensuring we can benefit from further diversity of thought and a more rounded expertise, not to mention energy. Thirdly, we will be looking to build on the initial momentum we have created in our first year, by running another event in June 2024,

Rally Round Rupert

'The Cotswold Way – 100 WALK 100'. If any volunteers or participants would like to join us, please reach out!

On behalf of the Trustees, it just leaves me to say a final and 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.

George Mosey

George Mosey

Chairperson of RALLY ROUND RUPERT

8th June 2024



End of Day 3 – 100 WALK 100 – The Cleveland Way

Rally Round Rupert

3. Our Mission

Charitable Purpose Statement:

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:

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

Public benefit

1. **Societal awareness** - By promoting societal awareness of 'Spinal Muscular Atrophy' (SMA), through our social media page ([Rally Round Rupert](#)) and our annual fundraising events, those affected by SMA and their families, now and in the future, will advance their understanding of this serious health condition - the leading genetic cause of infant death. This is particularly important, as earlier diagnosis of the condition and thereafter medical intervention, can significantly abate the impacts of SMA and drastically improve quality of life for those affected.
2. **Funding clinical research** - By raising much needed funds in support of clinical research, we will be able to advance the general body of knowledge associated with the condition. This is particularly important as there is no current cure for SMA. In addition, a range of healthcare professionals may be involved in the care of those with SMA, including specialist doctors, physiotherapists, occupational therapists and speech and language therapists, with current [treatments](#) including:
 - Exercise and equipment to help with movement and breathing
 - Feeding tubes and dietary advice
 - Braces or surgery to treat problems with the spine or joints
 - Medicines that target the faulty genes that cause the condition

Specifically, the trustees intend to focus on clinical research that will advance the understanding of healthcare professionals and medical practitioners (SMA specialist and non-specialist), caregivers of those with the condition, parents of children with the condition and those with SMA themselves, so that they are better able to manage and mitigate the [effects of the condition](#). Finally, this research will help ensure that those affected by the condition and their families, enjoy the best quality of life possible, wherever they may be in the world.

The beneficiaries

Delivering upon our purpose statement will benefit the public generally, as well, individuals suffering with SMA, healthcare and medical practitioners (SMA specialist and non-specialist), caregivers to those with SMA and parents / guardians of children with SMA.

We do not believe that any members of the public, including people in poverty, will be unreasonably restricted from accessing the awareness and research, by geography or other restrictions. We will ensure that the research in all instances, will be published (a prerequisite for funding) and made formally available to the global SMA community and the public generally.

Rally Round Rupert

4. Operational

Structure, Governance and Management

The charity is controlled by its governing document and a deed of trust and operates as a Charitable Incorporated Organisation (CIO). The Charity was registered on 25 January 2023.

- The Charity is run by the Trustees, who are elected members of the charity.
- There is a minimum of three, but a maximum of twelve Trustees.
- There are four formal Trustee meetings each year, but all Trustees participate in the informal communications in the interim periods.
- None of the Trustees received any remuneration for their services.
- The charity has no direct employees.

Trustee appointment

Additional Trustees may be appointed by the existing Trustees, either to replace a retiring Trustee or where it is felt that the Charity would benefit from additional skill sets and expertise. Following a selection process (skill set assessment), new Trustees will be taken through an induction programme covering the ethos, mission, governance, and financial background of the charity. They are also briefed on the role of a Trustee and Charitable law.

The charity has developed a pack for new trustees and as part of any appointment, new Trustees must complete a Trustee declaration form.

This includes:

- Administration
- What Rally Round Rupert does
- Governance and legal
- Trustees
- Financial and planning
- Charity Commission information

Rally Round Rupert

5. Financial review

Introduction and overview

The Trustees present their Annual Report and Financial Statements of the Charity for the year ended 24 January 2024. The trustees have adopted the provisions of 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).

The Trustees are pleased to present this report, outlining the charitable activities and objectives for the year ended 24 January 2024 and an overview of the financial performance and position for the year then ended.

The financial position of the Charity is strong, having raised **£188,798** in the year, and with **£183,074** of reserves as at 24 January 2024. The Charity held **£183,074** of cash at bank and in hand at the year end.

Future outlook

Following a successful year of fundraising for the Charity, it intends to commit to one or more clinical research projects in 2024, including £110,000 designated for a study into the nutritional needs of children with SMA. Further, given the huge success of the 100 WALK 100 event in June 2023, the Charity will be organising a similar event in June 2024.

The Board of Trustees remain committed to improving the understanding of SMA, while helping to advance clinical research.

Financial position

The Charity raises funds to meet its objectives, while maintaining financial stability. In its first year since registering as a charity, Rally Round Rupert generated **net income of £183,074**, with **£188,798 of trading activity income** from fundraising events, partially offset by charitable **activity costs of £5,411** and **costs of raising funds of £312**.

As at 24 January 2024, the Charity had **total net assets (equity) of £183,074**, which is all represented by cash at bank and in hand. All 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.

Rally Round Rupert

Independent Examiner's Report

to the Trustees of Rally Round Rupert

I report to the trustees on my examination of the accounts of Rally Round Rupert for the year ended 24 January 2024.

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').

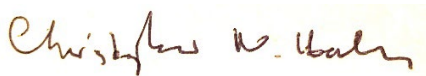
I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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 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

8th June 2024

Rally Round Rupert

| | Statement of financial activities | |
|--------------|--|--------------------|
| | For the year ended 24 January 2024 | |
| | | Year to 24.01.24 |
| | | Unrestricted funds |
| | | £ |
| Notes | Income | |
| | Donations and legacies | - |
| | Charitable activities | |
| 2 | Other trading activities - fundraising | 188,798 |
| | Total income | 188,798 |
| | | |
| | Expenditure | |
| 5 | Raising funds | (312) |
| 6 | Charitable activity costs | (5,411) |
| | Total expenditure | (5,724) |
| | | |
| | Net income | 183,074 |
| | | |
| | Net movement in funds | 183,074 |
| | Total funds brought forward | 0 |
| | Total funds carried forward | 183,074 |

| Balance Sheet | |
|--|----------------|
| As at 24 January 2024 | |
| | As at 24.01.24 |
| | £ |
| Total fixed assets | 0 |
| Cash at bank and in hand | 183,074 |
| Total current assets | 183,074 |
| Net current assets/(liabilities) | 183,074 |
| Total assets less current liabilities | 183,074 |
| Total net assets | 183,074 |

The notes on pages 11 to 12 form part of these accounts.

The accounts were approved by the Board of Trustees and signed on their behalf by:

George Mosey

George Mosey

Chairperson of RALLY ROUND RUPERT

8th June 2024

Rally Round Rupert

Notes to the financial statements For the year ended 24 January 2024

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 costs 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.

2 Other trading activities

Other trading activities consist entirely of income from fundraising events.

3 Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year end 24 January 2024.

4 Trustees' expenses

Rally Round Rupert

There were no trustees' expenses paid for by the charity for the year ended 24 January 2024.

5 Expenditure on raising funds

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

Expenditure on charitable activities

Expenditure on charitable activities relates to the following:

| | £ |
|--|--------------|
| Website costs | 26 |
| GoFundMe transaction costs | 5,385 |
| Total charitable activity costs | 5,411 |

6 Movement in funds

| | Brought forward | Income | Expenditure | Transfers | 24 January 2024 |
|---------------------|--------------------|----------------|----------------|-----------|--------------------------------|
| | £ | £ | £ | £ | |
| Unrestricted funds: | | | | | |
| General fund | - | 188,798 | (5,724) | (110,000) | 73,074 |
| Designated funds* | - | - | - | 110,000 | 110,000 |
| | | | | | - |
| Total funds | - | 188,798 | (5,724) | - | 183,074 |

*The designated funds are for research into the nutritional needs of children with SMA.

7 Related party disclosures

There were no related party transactions with any of the trustees for the year ended 24 January 2024.

8 Events after the reporting period

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

9 Independent examiner cost

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