

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Registered UK Charity No: 1186647

Registered Scottish Charity (SCIO) No: SC050921

ACCOUNTS

30TH JUNE 2024

Registered Address:

Smith-Magenis Syndrome (SMS) Foundation UK
61 High Street
Pewsey
Wiltshire
SN9 5AF

Operating and Registered Address in Scotland:

Smith-Magenis Syndrome (SMS) Foundation UK
28 Kilbrennan Drive
Tamfourhill
Falkirk
FK1 4SG

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

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THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Annual Report of the Trustees for the year ended 30th June 2024

The Trustees have pleasure in presenting their report together with the financial statements and the independent examiner's report for the year ended 30th June 2024.

Reference & Administrative Information

Charity Name	Charity Registrations
The Smith-Magenis Syndrome (SMS) Foundation UK CIO	UK Registered Charity No 1186647 Registered Scottish Charity SC050921

Registered Address

The Smith-Magenis Syndrome (SMS) Foundation UK,
61 High Street, Pewsey, Wiltshire, SN9 5AF

Operating and Registered Address in Scotland

The Smith-Magenis Syndrome (SMS) Foundation UK,
28 Kilbrennan Drive, Tamfourhill, Falkirk, FK1 4SG

Trustees

Name	Elected	Re-Elected	Resigned
Hazel Wotherspoon (Chairperson)	16/11/2019	25/01/2022	
Emma Riddell	16/11/2019	25/01/2022	
Mick Pearson	16/11/2019	25/01/2022	
Laura Maddocks	12/01/2021		
Wendy Ferguson	12/01/2021		17/04/2024
Jayne Dainty	25/01/2022		
Jacqueline Jenkins	07/06/2023		

Debbie Brooks is a co-opted non-trustee member of the Board.

Structure, Governance & Management

Constitution

The Smith-Magenis Syndrome (SMS) Foundation UK CIO, 1186647, is a Charitable Incorporated Organisation (CIO). It is governed by its Foundation constitution which was adopted on 16th November 2019. The Smith-Magenis Syndrome (SMS) Foundation UK CIO became registered with the Charities Commission on 28th November 2019, and with OSCR as a Scottish Charitable Incorporated Organisation (SCIO) SC050921 on 21st April 2021.

Appointment of Trustees

Trustees are elected at the Annual General Meeting to serve for terms of three years. Retiring trustees are eligible to stand for re-election. The constitution states that there must be no fewer than three trustees. A minimum of one-third of the trustees are to have a direct family connection to Smith-Magenis syndrome.

Management

The Trustees are responsible for the strategic direction and governance of the charity, and for the delivery of charitable activities to meet the objectives.

A small part-time team is employed to run day-to-day operations. At the date of signing this report, this team comprises:

- Communications Manager & Programmes Lead: Leeann Stevenson
- Fundraising Manager: Helen Hargrave
- Research & Sector Engagement Manager: Natasha Craven
- Fraser Cardow: Fundraising Manager (trusts and foundations) (contractor)

Objectives & Activities

Charitable Purposes

The charity's objects ("the objects") are:

1. To preserve and protect the health and promote the relief of persons affected by Smith-Magenis Syndrome and any associated condition,
2. To advance the education of the medical profession and the general public on the subject of Smith-Magenis Syndrome and its implications for the family,
3. To advance public education by promoting research into the management of Smith-Magenis Syndrome and to publish the useful results thereof and to support organisations promoting research into Smith-Magenis Syndrome.

Background

The SMS Foundation UK ("The Foundation") was set up as a parent support group in 1992 and until 2019 operated as an entirely volunteer-led, small, registered charity. The Trustees agreed that more resources and income would be required to meet the increasing demands and needs of the SMS community. It was decided to change the charity status to a CIO (Charitable Incorporated Organisation) to minimise personal risk, maximise financial potential and introduce staff to support and grow service delivery. In 2019, the Foundation UK began the transition to dissolve the UK and Scottish unincorporated charities and register as a CIO in England and SCIO in Scotland and completed this in April 2021.

Achievements & Performance

In the financial year 2023-2024 our charity has made significant strides in supporting the Smith-Magenis Syndrome (SMS) community through dedicated outreach, engagement, and collaboration. Here's a snapshot of our key achievements:

Community Support and Engagement

- Our team of staff and volunteers has been highly responsive, addressing 198 incoming enquiries (via emails, messages, and phone).
- We are proud to have seen a 14% growth in our family and professional membership, further strengthening our support network.
- Digital engagement continues to rise, with a 3.4% increase on Facebook and a 2.7% increase on Instagram, broadening our reach and engagement with the SMS community.
- A key highlight of the year was launching a new initiative celebrating the lives of individuals with SMS. Seven articles were published, all contributing to increased website traffic and deeper community engagement.

Partnerships and Collaborations

- We have strengthened relationships within the rare disease community, establishing new partnerships with Parent Advisory Groups and umbrella organisations. We are also working alongside six other charities to challenge discriminatory legislation and advocate for the disability rights of the SMS community.
- Our ongoing collaboration with The Cerebra Network continues, particularly through the Beond project, which aims to enhance understanding of behaviour, wellbeing, cognition, and health within the SMS population.
- Additionally, we are partnering with Cambridge University on a 3-year research project focusing on the physical and mental health needs of those living with SMS.

Outreach and Awareness

- This year, our staff and pastoral care volunteers delivered seven SMS awareness sessions in education settings and care homes, raising awareness and offering valuable insights into supporting individuals with SMS.

New Initiatives and Services

- To support our pastoral care team, we have partnered with RareMinds, a specialised counselling service for the rare disease community, set to roll out in November 2024.
- To assist families navigating the educational system, we have developed a partnership with SEND Consultant Annette Benstead, launching a 1:1 EHCP service in November 2024 following the success of a pilot case earlier this year.

Financial Review

Extensive efforts were made to raise funds and support for the Foundation throughout the year. Income of £81,579 was received this year. £33,491 came from grants, £48,005 came through charitable donations, legacy, and general fundraising activities, and £83 was received in bank interest.

Expenditure for the year totalled £84,648. This was spent as follows:

- £54,140 on total staff costs.
- £20,555 on costs for a national event for members planned for August 2024.
- £4,606 on administration, insurance, software licences and membership subscriptions.
- £1,936 on staff and trustee training and development.
- £2,949 for fundraising activities. This included fundraising platform subscriptions, promotional materials, merchandising items, and event entries.
- £62 on banking costs.
- £400 in a grant to an SMS family towards the cost of kitchen equipment.

Cash balances at the year-end amounted to £33,895, of which £8,413 is restricted funding. Further detail on income and expenditure and the purpose of the restricted funding held at the year-end is shown on pages 11 to 13.

Reserves Policy

The intention of the Foundation is to seek to retain a minimum of 12 months of core operating expenditure as the basis of its cash reserves, excluding restricted funding for projects.

At the year end, the Foundation held unrestricted cash reserves covering 6 months of core operating costs. Core operating costs exclude the costs of employees who will be directly working on already funded projects in the year ahead.

The Foundation is working to increase its cash reserves to the 12-month targeted level.

Plans for Future Periods

National Event 2024

Preparations are well underway for our upcoming National Event in August 2024 at The Mount Cook Activity Centre in Derbyshire. This year, we are excited to pilot an initiative that puts individuals with SMS at the heart of the event, offering family-friendly activities and vital information.

As we look forward to the coming year, we remain committed to supporting and advocating for the SMS community through innovative programmes, partnerships, and outreach efforts.

Approved by the trustees and signed on their behalf by:



Hazel Wotherspoon – Chairperson

Date: 28th March 2025

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Independent Examiner's Report to the Trustees of
THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO
For the year ended 30th June 2024

Independent Examiner's Report on the Accounts

Report to the trustees / members of: The Smith-Magenis Syndrome (SMS) Foundation UK CIO
On accounts of the charity for: 1st July 2023 to 30th June 2024
Charity Registration: Registered UK Charity 1186647
Scottish Registered Charity (SCIO) SC050921
Set out on pages: Pages 9 to 13

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006.

The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 and that the audit requirement of Regulation 10(1) (d) of the Charities Accounts (Scotland) Regulations 2006 does not apply.

It is my responsibility:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act), and
- examine the accounts as required under section (44)(1) (c) of the Charities and Trustee Investment (Scotland) Act 2005
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission and with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006.

An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that in, any material respect, the requirements:
 - to keep accounting records in accordance with section 130 of the Charities Act 2011 and with section 44(1)(a) of the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006; and

- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act 2011 and Regulation 9 of the Charities Accounts (Scotland) Regulations 2006

have not been met; or

2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed:  Date: 31st March 2025

Name: Julie Russell

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

Address: 34 Orchard Drive, Edinburgh, EH4 2DZ

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO, 1186647

Accounts for the period 1st July 2023 to 30th June 2024

Statement of Receipts and Payments Account (General Purpose Fund)

Receipts and Payments Account: General Fund

		£	£	£	£
		Unrestricted	Restricted	Total	Total
<u>Receipts</u>	Note	Funds	Funds	2024	2023
<u>Voluntary Sources</u>					
Donations and membership fees	8	11,300	-	11,300	36,690
Legacies	8	5,000	-	5,000	9,523
Grants	4	17,101	16,390	33,491	16,955
Receipts from fundraising activities	8	25,102	-	25,102	18,925
Gross receipts from trading		208	-	208	785
Income from investments		83	-	83	67
Organised Event Income	9	6,395	-	6,395	38
Total Receipts / Income		65,189	16,390	81,579	82,983
<u>Payments</u>					
Expenses for fundraising activities	8	2,949	-	2,949	5,432
Gross Trading Payments	8	-	-	-	290
Banking / Investment costs		62	-	62	70
Payments relating directly to charitable activities:					
Staff Costs	5	29,322	24,818	54,140	76,712
Training & Development Costs	5	1,936	-	1,936	1,201
Research Costs	5	-	-	-	1,621
Administration & Office Costs	5	1,680	-	1,680	591
Software Licences	5	2,329	-	2,329	2,248
Insurance	5	-	-	-	157
Equipment		-	-	-	-
Subscriptions		597	-	597	-
Publications	7	-	-	-	-
Events	9	20,555	-	20,555	200
Grants	10	-	400	400	1,205
Governance Costs	13	-	-	-	-
Trustee Expenses	6	-	-	-	-
Total Expenditure / Payments		59,430	25,218	84,648	89,727
Total Receipts		65,189	16,390	81,579	82,983
Total Payments		59,430	25,218	84,648	89,727
Surplus / (Deficit) for the year		5,759	(8,828)	(3,069)	(6,744)
Transfers between funds	12	-	-	-	-
Surplus / (Deficit) for the year		5,759	(8,828)	(3,069)	(6,744)

The Notes on pages 11 to 13 form an integral part of these accounts.

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Statement of Balances on Assets and Liabilities at 30th June 2024

	£ Unrestricted Funds	£ Restricted Funds	£ Total 2024	£ Total 2023
<u>Fund Reconciliation</u>				
Cash at Bank & In Hand – start of year	19,723	17,241	36,964	43,708
Surplus / (Deficit) for the year	5,759	(8,828)	(3,069)	(6,744)
Cash at Bank & In Hand – end of year	25,482	8,413	33,895	36,964

Bank & Cash Balances

CAF Bank Account			33,328	32,671
PayPal Account			567	4,293
Cash in Hand			-	-
			33,895	36,964

Other Assets (Unrestricted Fund)

There are no other assets

	-	-
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Liabilities (Unrestricted Fund)

No current unrestricted fund liabilities

	-	-
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Liabilities (Restricted Fund)

No current restricted fund liabilities

	-	-
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The Notes on pages 11 to 13 form an integral part of these accounts.

Approved by the Trustees and signed on their behalf by:



Hazel Wotherspoon (Chairperson)

Date: _____ 28th March 2025

Notes to the Accounts – For the Year Ended 30th June 2024

1. Basis of Accounting

These accounts have been prepared on the Receipts & Payments basis in accordance with the Charities Act 2011, Charities & Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended).

2. Nature and purpose of the funds

Unrestricted funds are those that may be used at the discretion of the trustees in furtherance of the objects of the charity. The trustees maintain a single fund for the running of the charity.

Restricted funds may only be used for specific purposes. Restrictions arise when specified by the donor or when funds are raised for specific purposes. During the year, the charity received some restricted funding in the form of grants and donations.

3. Related Party Transactions

The charity's insurance policy includes Trustee Indemnity for all its trustees. No other remuneration was paid to the trustees or to any connected persons during the year.

4. Grants and Donations

The following grants were received in prior years and spent in 2023-2024:

Grant	Provider	Purpose	Used for
£5,000	Mercers Company	Expansion and development of the Volunteer Engagement Strategy	Staff costs associated with the development of content and materials
£3,828	The National Lottery Community Fund	The Scottish Volunteer Engagement Plan and a programme of awareness training modules for Scotland	Staff costs associated with volunteer engagement and training
£8,828			

The following grants and donations were received in 2023-2024: (Total £33,491, all of which was spent in the year)

Amount	Provider	Purpose	Used for
£1,500	Flynn Pharma	Unrestricted	To fund core costs
£4,000	Hugh Fraser Foundation	To fund work associated with volunteer engagement	Staff costs associated with the expansion and development of the Volunteer Engagement Strategy
£5,000	Robertson Trust	Unrestricted	To fund core costs
£9,990	The National Lottery Community Fund	The carer support service	Staff costs associated with the carer support service
£2,000	Albert Hunt	Carer support costs	Staff costs associated with the carer support service
£400	Independence at Home	To support someone with independent living	A grant to someone with SMS to support them at home

Amount	Provider	Purpose	Used for
£1,000	Sylvia Aitken Trust	Unrestricted	To fund core costs
£4,601	Benevity	Unrestricted	To fund core costs
£5,000	The Bailey Thomas Charitable Trust	Unrestricted	To fund core costs
£33,491			

The following restricted grants and donation balances are being held for use in future years:

Grant	Provider	Purpose
£536	Private Donation	To help families attend the conference
£5,127	The National Lottery Community Fund	The Scottish Volunteer Engagement Plan and a programme of awareness training modules for Scotland
£2,000	Meikle Foundation	Two in-person family events
£750	Private Donation	To help families attend the conference
£8,413		

5. Administration Costs

These are the costs of running the charity and are as follows:

- Software licences £2,329. These relate to a membership database and an electronic mailing application.
- Staff training and development £1,936.
- Payroll bureau, HR platform, website and stationery and postage £1,680.

Staff Costs

Average number of staff employed: 4 (1.8 FTE)
 Period of employment: 1st July 2023 to 30th June 2024
 Staff salaries including taxes and pensions: £54,140
 No member of staff has a salary above £60,000 p.a.

6. Trustee Expenses

No Trustees claimed expenses during the reporting period.

Travel and subsistence costs related directly to other activities and services of the Foundation has been included within the costs for these items.

Reimbursement of expenditure on direct purchases on behalf of the charity is recorded under Administration.

No professional or legal fees were incurred during the year.

7. Publications

The charity has moved to electronic publishing through the website and social media removing printing of newsletters and other materials.

8. Fundraising

Donations are recorded based on receiving an altruistic gift, either with a general charitable purpose, or for the support of a project. Fundraising includes all member led activities where contributions have been acquired or requested in respect to these activities. Fundraising also includes the text to donate campaigns run by the charity.

The Foundation received donations totalling £11,300 from various individuals and organisations with the highest single donation being for £3,225.

Income raised by the SMS community totalled £25,102. Expenses for fundraising activities relate to expenditure on sports event entry fees, fundraising merchandise and donation platform fees and subscriptions and totalled £2,949

In memorial donations (also known as legacies) were £5,000.

Gross receipts from trading comprise sales of awareness merchandise through the charity's online shop of £208.

9. Events

The charity has spent £20,555 in relation to its national event which is taking place in August 2024. Members have contributed £6,395 towards these costs in this financial period.

10. Grants

One grant to improve the life of a person with Smith-Magenis syndrome and their family was secured and paid totalling £400. This was towards the cost of an induction hob. The grant was funded by Independence at Home.

11. Research

There were no costs incurred in undertaking research this year.

12. Transfers between funds

No transfers are recorded as taking place between funds during the year.

13. Governance Costs

No governance costs were incurred during the year.