

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Registered UK Charity No: 1186647

Registered Scottish Charity (SCIO) No: SC050921

ACCOUNTS

31st December 2025

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 31st December 2025

The Trustees have pleasure in presenting their report together with the financial statements and the independent examiner's report for the year ended 31st December 2025.

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: Hazel Wotherspoon
Address: 28 Kilbrennan Drive
Tamfourhill
Falkirk, FK1 4SG
Email Address: hazel@smith-magenis.co.uk
Telephone Number: 07952047894
Date of Birth: 07/10/1952
Date of Appointment Elected: 6/11/2019 Re-elected 25/01/2022

Name: Emma Riddell
Address: 3 Avro Way
Castle Vale
Birmingham B35 7NW
Email Address: Emma@smith-magenis.co.uk
Telephone Number: 07980833904
Date of Birth: 29/11/1979
Date of Appointment Elected: 16/11/2019 Re-elected 25/01/2022

Name: Mick (Michael) Pearson
Address: 20 Hatherleigh Close
Bognor Regis
West Sussex, PO21 5JA
Email Address: mick@smith-magenis.co.uk
Telephone Number: 07717560479
Date of Birth: 26/06/1978
Date of Appointment Elected: 16/11/2019 Re-elected 25/01/2022

Name: Jacqueline Jenkins
Address: 26 Hollicondane Road
Ramsgate
CT11 7PH
Email Address: Jacqui@smith-magenis.co.uk
Telephone Number: 07968873544
Date of Birth: 03/07/1978
Date of Appointment: 07/06/2023

Name: Jayne Dainty
Address: 6 Pasture View
Pelsall
Walsall, WS3 4NP
Email Address: Jayne@smith-magenis.co.uk
Telephone Number: 07843391751
Date of Birth: 24/11/1972
Date of Appointment Elected: 25/01/2022 Re-elected 05/02/2025

Name: Alvar de Wolff
Address: 18 Avenue Gardens
London, W3 8HA
Email Address: alvardewolff@gmail.com
Telephone Number: 07584601743
Date of Birth: 24/06/1981
Date of Appointment: 05/02/2025

Name: Andrew Joseph Bird
Address: 73 Cutlers Place
Wimborne
Dorset, BH21 2HX
Email Address: andrewjosephbird@gmail.com
Telephone Number: 07362271963
Date of Birth: 05/09/1969
Date of Appointment: 05/02/2025

Name: Alistair Hudson
Address: 1 Tiger Moth Road
Sealand
Flintshire, CH5 2FN
Email Address: alz.hudson@gmail.com
Telephone Number: 07595222428
Date of Birth: 19/03/1985
Date of Appointment: 05/02/2025

Name: Laurie Grainger
Address: 360 Bennett Street
Long Eaton
Nottingham, NG10 4JD
Email Address: lauriegrainger@hotmail.co.uk
Telephone Number: 07773092313

Date of Birth: 04/09/1975
Date of Appointment: 05/02/2025

Name: Bill (William) Stevenson
Address: 5 St Chad's Avenue
Midsomer Norton
Radstock, BA3 2HG
Email Address: bill.stevenson@smith-magenis.co.uk
Telephone Number: 07886461909
Date of Birth: 19/09/1949
Date of Appointment: 01/02/2025

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:

- Executive Director: Leeann Stevenson
- Programmes Manager: Helen Hargrave
- 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

Over the 18-month period for the financial year 1st July 2024 to 31st December 2025 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:

Carer Support Programme

- 416 enquiries handled between October 2024 and December 2025.
- 10 referrals made to Rare Minds for parent and caregiver counselling.
- 11 one-to-one professional advice consultations provided (SMS clinics at Mount Cook).
- Relationships established with Rare Minds, SEND Consultancy Ltd and Plain Thinking Ltd to deliver counselling, education advice, resources and training.

Events and community support

- Three family events delivered:
 - Mount Cook, August 2024: 64 attendees
 - Avon Tyrrell, July 2025: 77 attendees
 - Lockerbie Manor, September 2025: 26 attendees
- 167 attendances recorded across the three events.
- 31 separate individuals with SMS accessed inclusive activities.
- The events gave parents and carers opportunities for peer support, while individuals with SMS and their siblings participated in accessible activities.

Information and resources

- 21 online resources published.
- Articles and resources covered education, health, behaviour, family support and practical guidance.
- Content was written by staff and commissioned from professionals with relevant expertise.
- A new medical information poster was produced, with content adapted for the website and social media.
- Work continued to strengthen information and volunteer support for families in Scotland.

Education Support Programme

- Eight training sessions delivered.
- 59 professionals trained to improve their understanding of SMS and the support individuals may require.
- One-to-one education consultations were provided through SEND Consultancy Limited.
- An Annual Review webinar was delivered with SEND consultant Annette Benstead in June 2025.
- Educational articles, online resources and training materials were developed to help families navigate SEND systems.
- Relationships were developed with SEND and legal advocacy professionals to strengthen the support available to families.

Webinars

- Four webinars delivered.
- 273 registrations received across the webinar programme.
- Topics included education, research, health and practical support for families.

Membership and reach

- 28 new SMS membership registrations received during the reporting period.
- The Foundation continued to expand its reach through online information, webinars, events, training and direct family support.

Research and partnerships

Work during the period included:

- Supporting the Cerebra Network's BeOND research programme.
- Working with the University of Cambridge on the SMS Springboard project.
- Maintaining relationships with PRISMS, Unique and Genetic Alliance UK.
- Developing links with CVI Now at Perkins to improve information about cerebral visual impairment.
- Strengthening the Professional Advisory Board and professional input into family information and support.

Reserves Policy

Following the COVID pandemic and updated guidance from the Chartered Institute of Fundraising and the Charity Commission, the Trustees reviewed the Foundation's Reserves Policy during the financial period. The policy now aims to maintain unrestricted reserves equivalent to a minimum of three months' average core expenditure.

The reserves target is calculated using core salary and operational costs, excluding salaries and other expenditure covered by restricted project funding. The Finance Sub-Committee reviews the position monthly, taking account of current core expenditure and the level and duration of restricted funding remaining, and adjusts the calculation where necessary.

If unrestricted reserves fall below the three-month target, a reporting procedure is in place to alert the Board and seek its guidance where required. This approach enables the Foundation to monitor its financial position closely and respond appropriately to changes in funding and the wider fundraising environment.

At the period end, the Foundation held £24,744 in restricted funds and £6,615 in unrestricted funds. A further £5,680 of unrestricted income was awaiting release from GoFundMe to our PayPal account, comprising £4,500 from a paddleboard fundraiser and £1,180 from a Santa-thlon. Including these delayed receipts, unrestricted reserves were £12,295, equivalent to approximately five months of average core expenditure.

Change to the financial reporting period

During the period, the trustees agreed to change the Foundation's financial year to align with the calendar year, supporting clearer project planning, funding allocation and financial management. The reporting period was therefore extended by six months, from 30 June 2025 to 31 December 2025. This Annual Report and Financial Statements consequently **cover an 18-month period from 1 July 2024 to 31 December 2025**. The next annual reporting period will run from 1 January to 31 December 2026.

Plans for Future Periods

National Event 2026

Preparations are well underway for our residential National Event in June 2026 at Barnstondale Activity Centre in the Wirral. This year, we are excited to bring professionals, caregivers and individuals with SMS at the heart of the event, offering family-friendly activities and vital information sharing sessions.

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: 11th September 2026

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 31st December 2025

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 2024 to 31st December 2025
Charity Registration: Registered UK Charity 1186647
Scottish Registered Charity (SCIO) SC050921
Set out on pages: Pages 11 to 16

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 to:

- examine the accounts under section 145 of the Charities Act,
- 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
- 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: 2nd September 2026

Name: Glyn Pearce BSc (Hons), MAAT

Relevant professional
qualification(s) or body (if any): Association of Accounting Technicians

Address: 14 Magnolia Road, Westfield, Radstock. BA3 3EX

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

Accounts for the period 1st July 2024 to 31st December 2025

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	2025	2024
<u>Voluntary Sources</u>					
Donations	8	39,910	-	39,910	11,300
Legacies		0	-	0	5,000
Grants	4	3,300	120,401	123,701	33,491
Receipts from fundraising activities	8	20,815	-	20,815	25,102
Gross receipts from trading		731	-	731	208
Income from investments		115	-	115	83
Organised Event Income	9	5,299	-	5,299	6,395
Total Receipts / Income		70,170	120,401	190,571	81,579
<u>Payments</u>					
Expenses for fundraising activities	8	32,494	-	32,014	2,949
Gross Trading Payments	8	706	-	706	-
Banking / Investment costs		90	-	90	62
Payments relating directly to charitable activities:					
Staff Costs	5	39,921	56,295	96,216	54,140
Training & Development Costs	5	-	3,672	3,672	1,936
Admin, Office Costs, Software	5	3,127	2,416	5,543	1,680
Insurance	5	520	-	520	-
Equipment	5	768	-	768	-
Subscriptions		126	-	126	597
Publications & Resources	7	-	5,523	5,523	-
Community Support (+SLAs)	12		15,320	15,320	
Events	9	11,659	20,110	32,249	20,555
Grants	10	360	-	360	400
Governance Costs	14	-	-	-	-
Trustee Expenses	6	-	-	-	-
Total Expenditure / Payments		89,771	103,337	193,107	84,648
Total Receipts		70,170	120,401	190,571	81,579
Total Payments		89,771	103,337	193,107	84,648
Surplus / (Deficit) for the 18 mths		(19,600)	17,064	(2,536)	(3,069)
Transfers between funds	13	-	-	-	-
Surplus / (Deficit) for the 18 mths		(19,600)	17,064	(2,536)	(3,069)

The Notes on pages 14 to 16 form an integral part of these accounts.

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Statement of Balances on Assets and Liabilities at 31st December 2025

	£ Unrestricted Funds	£ Restricted Funds	£ Total 2025	£ Total 2024
<u>Fund Reconciliation</u>				
Cash at Bank & In Hand – start of year	26,215	7,679	33,895	36,964
Surplus / (Deficit) for the year	(19,600)	17,064	(2,536)	(3,069)
Cash at Bank & In Hand – end of year	6,615	24,744	31,359	33,895

Bank & Cash Balances

CAF Bank Account	31,314	33,328
PayPal Account	46	567
Cash in Hand	-	-
	31,360	33,895

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: 11th September 2026

Notes to the Accounts – For the Year Ended 31st December 2025

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 2024-2025:

Grant	Provider	Purpose	Used for
£536	Private Donation	To help families attend the conference	SMS Family Activity Day at Mount Cook (July 2024)
£2,000	Meikle Foundation	Two in-person family events	SMS Family Activity Day at Lockerbie (Sep 2025)
£750	Private Donation	To help families attend the conference	SMS Family Activity Day at Mount Cook (July 2024)
£3,286			

The following grants and donations were received in 2024-2025: (Total £118,401, all of which was spent in the year)

Amount	Provider	Purpose	Used for
£5,000	Robertson Trust	Unrestricted	To fund core costs
£67,407	The National Lottery Community Fund	Carer support service & Education Programme	Enquiries & counselling, Clinics and Patient Passport, Training, Events & Activities, Education Online Services, 1:1 EHCP Referral Service
£10,000	Foyle Foundation	Unrestricted	To fund core costs
£18,640	Jeans 4 Genes	Carer support service & Education Programme	Enquiries & counselling, Training, 1:1 EHCP Referral Service
£5,354	Cambridge University	Family Event	To bring families together and share information for Cambridge Springboard project
£5,000	Agnes Hunter	Carer support service & Education Programme (Scotland)	Enquiries & counselling, Training, Events & Activities,

Amount	Provider	Purpose	Used for
			Education Online Services, Education Referral Service
£4,000	Hugh Fraser Foundation	Carer support service & Education Programme (Scotland)	Enquiries & counselling, Training, Events & Activities, Education Online Services, Education Referral Service
£3,000	Flynn Pharmaceutical	Donation	Support Education Service and Training
£118,401			

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

Grant	Provider	Purpose
£5,127	The National Lottery Community Fund	The Scottish Volunteer Engagement Plan and a programme of awareness training modules for Scotland
£5,127		

5. Administration & Equipment Costs

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

Unrestricted

- Software licences £1,685 relate to HR platform, electronic mailing and graphics applications.
- Payroll bureau (SCVO) £1098
- Postage £345
- Laptop replacement, printer heads and office equipment £768

Restricted

- Membership database (CRM) & Enquiries £2,416

Staff Costs

Average number of staff employed: 4 (1.6 FTE)
 Period of employment: 1st Jul 2024 to 31st Dec 2025
 Staff salaries (employees) including taxes and pensions: £96,216
 Fundraising (contractor) (see 8 Fundraising Activities): £23,940
 No member of staff has a salary above £60,000 p.a.

Staff costs increased by approximately £28,000 compared with the previous reporting period. However, the current accounts cover 18 months rather than 12 months and are therefore not directly comparable. During the period, staff hours were initially reduced in response to lower unrestricted reserves and were subsequently increased following the award of the National Lottery grant and other restricted grants, enabling the Foundation to deliver the funded projects. Of the total staff costs of £96,215, £56,295 related to project-funded salaries and £39,920 to core-funded salaries.

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 and Resources

We spent £5,523 of restricted Education Programme funding on producing and publishing articles and resources. These covered a range of topics and were written by staff or commissioned from experienced professionals.

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.

The Foundation received donations totalling £39,910 from various individuals and organisations with the highest single donation being for £6,764.

Income raised by the SMS community totalled £20,815. Expenses for fundraising activities relate to expenditure on sports event entry fees, fundraising merchandise and donation platform fees and subscriptions and totalled £8,074.

We spent £23,940 on our Trusts and Foundations Fundraising Manager, supporting the development of grant applications and income from charitable trusts and foundations.

Gross receipts from trading comprise sales of awareness merchandise through the charity's online shop of £706.

9. Events

Over the 18-month period, we delivered three family events: Mount Cook in August 2024, supported by £11,609 of unrestricted funds; Avon Tyrrell in July 2025, costing £9,513 from restricted funds; and Lockerbie in September 2025, costing £4,999 from restricted funds. Additional event expenditure included a deposit of £5,597.70 towards our 2026 event near Liverpool.

Members contributed a further £5,021 in entry fees towards the Avon Tyrrell and Lockerbie events.

10. Grants

One grant to improve the life of a person with Smith-Magenis syndrome was secured and paid totalling £360. This was towards the cost of a waterproof mattress.

11. Research

There were no costs incurred in undertaking research this year.

12. Community Support & SLAs

Over the 18-month period, we developed service-level agreements with three providers: Rareminds for parent and caregiver counselling, SEND Consultancy Services for specialist one-to-one education advice, and Plain Thinking for educational resources and training materials. We spent £15,320 in total, including £5,935 on counselling, with the remaining £9,385 supporting education referrals, online resources and training materials.

13. Transfers between funds

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

14. Governance Costs

No governance costs were incurred during the year.