

**THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO**

Registered UK Charity No: 1186647

Registered Scottish Charity (SCIO) No: SC050921

**ACCOUNTS**

**30<sup>TH</sup> JUNE 2022**

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**Registered Address:**

Smith-Magenis Syndrome (SMS) Foundation UK  
18 Suthmere Drive  
Burbage  
Marlborough  
SN8 3TG

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**Operating and Registered Address in Scotland:**

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

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**THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO**

**Contents of the Financial Statements**

**For the year ended 30<sup>th</sup> June 2022**

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## THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

### Annual Report of the Trustees for the year ended 30<sup>th</sup> June 2022

The Trustees have pleasure in presenting their report together with the financial statements and the independent examiner's report for the year ended 30<sup>th</sup> June 2022.

#### 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,  
18 Suthmere Drive, Burbage, Marlborough, SN8 3TG

#### 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	
Nick Hunt	16/11/2019		03/10/2022
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		
Rosina Mosedale	25/01/2022		13/01/2023
Jayne Dainty	25/01/2022		

Two individuals have been co-opted as non-trustee members of the board: Jacqueline Jenkins and Debbie Brooks.

#### 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 16<sup>th</sup> November 2019. The Smith-Magenis Syndrome (SMS) Foundation UK CIO became registered with the Charities Commission on 28<sup>th</sup> November 2019, and with OSCR as a Scottish Charitable Incorporated Organisation (SCIO) SC050921 on 21<sup>st</sup> 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 for 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. This team comprises:

- Information & Communications Manager: Leeann Stevenson
- Fundraising Manager: Helen Hargrave
- Research & Admin Assistant: Natasha Craven

## **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

During the reporting period, the Foundation continued to deliver activities to meet its charitable purposes as follows:

1. Family membership has grown by 43%, and overall reach has increased by 10%. A new subscriber option has been created for individuals to join our mailing list for our latest news and information.
2. Delivery of a four-day conference for families and professionals working with SMS in April/May 2022 (postponed from 2021 due to Covid-19).
3. Handled 84 enquiries and demand for support from families and professionals.
4. Provided funding of £500 to family towards a hydrotherapy bath improve the quality of life their son with SMS.
5. Promotion of the regular giving scheme 'SMS 1711 Circle' which is currently generating a monthly income of £226.
6. Continued to embed our Regional Parent Supporters (RePS) programme.
7. Hosted internship project on understanding vision and visual impairments in SMS.
8. Launched internship projects covering education, behaviours, transitions, medical matters, obesity in SMS, adult residential options, and impact of genetic diagnosis.
9. Pro-active participation in Patient Engagement and Advisory Groups on the implementation plans for the UK Rare Disease Framework.

10. Delivered training sessions into schools to directly support SMS children in the classroom, NHS learning disability teams, care organisations, and adult day service provider.
11. Updated the website to include specific information to help families, developed and written a blog 'Spotlight on SMS' featuring articles about sleep and eyesight.
12. Increased social media following across all platforms, with a 23% rise in Facebook following (primary account), and an increase in post reach of 471%.
13. Supported regional community social events.
14. Continued to develop our digital strategy, including the implementation of CRM Beacon for membership management.

## **Financial Review**

Extensive efforts were made to raise funds and support for the Foundation throughout the year. £105,691 was received this year. £35,228 came from grants. £47,119 through charitable donations and general fundraising activities, and £23,345 was received towards the cost of accommodation and delegate fees for our conference.

Expenditure for the year totalled £135,109. This was spent as follows:

- £77,699 on total staff costs.
- £44,738 on the delivery of a conference for SMS families and professionals working with SMS.
- £4,948 on administration, insurance, software licences and membership subscriptions.
- £3,918 on awareness merchandise and distribution costs
- £3,210 for fundraising activities. This included enhanced fundraising platform subscriptions, promotional materials, merchandising items, and event entries.
- £500 towards equipment costs to improve the life of a person with SMS.

Cash balances at the year end amounted to £43,708, of which £10,222 is restricted funding.

## **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. However, in light of the impact of Covid-19 and the move to employing staff members immediately followed by the pandemic, Trustees agreed that the Foundation could operate with 6 months of reserves as a reasonable position under those circumstances, and work to grow this to the 12-month level. Should unrestricted reserves fall to 3 months of core operating costs then contingency measures would be implemented to lower planned expenditure to sustain the charity for at least one year.

At the year end, the Foundation held reserves covering 5.4 months of core operating costs.

## **Reserves post year end**

The Foundation continues to secure funding and is supported by the incredible efforts of many supporters, making it possible to deliver important support to families and those with SMS. However, the pandemic and cost-of living crises have made fundraising very competitive. As a result, the reserves position deteriorated post year end which necessitated a reduction in the size of the part-time staff team and the role of CEO was made redundant.

## Plans for Future Periods

An old proverb gave us inspiration... "It takes a village to raise a child". We understand the complex needs of a person with SMS and recognise what it takes to give them the support they need. It takes a community of people including family, friends, peers, doctors, nurses, practitioners, and teachers. This got us thinking... What if we could build our own village?

Our purpose is to ensure that every person with SMS is supported by a village of caregivers and professionals who are equipped and empowered with the knowledge and understanding to meet their needs.

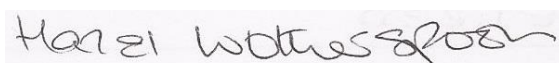
During the next financial year, the Foundation intends to continue to deliver activities to meet the objects of the charity, whilst we also plan out our virtual 'SMS Village' with the definition of our five-year development plan and put in place the infrastructure on which to build our ambition. Our medium to long term focus shall be on:

- Supporting families and carers
- Providing support for education
- Raising awareness and understanding through enhanced training programmes
- Communicating medical matters
- Bringing families and professionals together through our events

We shall support our SMS community and lay our foundations for future development by:

1. Prioritising our community's needs with a focus on:
  - Carer support service
  - Education support services
  - Training programme
  - Events programme
  - Medical information packs
2. Enhancing our knowledge through continuing to offer internship projects with emphasis on medical awareness, health, behaviour, diet and obesity, education, transitions, and adult life.
3. Build networks with other organisations to grow collaborative opportunities, bringing our knowledge and experience to help shape wider policies and services.
4. Strengthen our core team by bringing new skills to the board, volunteers, and staff. Utilise pro bono experts to help in our development.
5. Grow our membership and supporter base.
6. Improve sustainability by increasing income generation.
7. Improve engagement and strengthen brand, through the development of our communication strategy, engagement strategy, corporate and brand guidelines, and resources.

Approved by the trustees and signed on their behalf by:



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Hazel Wotherspoon – Chairperson

Date: 19<sup>th</sup> March 2023

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 30<sup>th</sup> June 2022**

**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: 1<sup>st</sup> July 2021 to 30<sup>th</sup> June 2022  
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: Julie H Russell Date: 19<sup>th</sup> March 2023

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 1<sup>st</sup> July 2021 to 30<sup>th</sup> June 2022**

**Statement of Receipts and Payments Account (General Purpose Fund)**

**Receipts and Payments Account: General Fund**

	Note	£ Unrestricted Funds	£ Restricted Funds	£ Total 2022	£ Total 2021
<b><u>Receipts</u></b>					
<b><u>Voluntary Sources</u></b>					
Donations and membership fees	8	24,203	-	<b>24,203</b>	2,286
Legacies	8	989	-	<b>989</b>	115
Grants	4	-	35,228	<b>35,228</b>	51,633
Receipts from fundraising activities	8	19,859	-	<b>19,859</b>	22,639
Gross receipts from trading		2,062	-	<b>2,062</b>	329
Income from investments		4	-	<b>4</b>	-
Organised Event Income	9	23,345	-	<b>23,345</b>	450
Gross Receipts from other activity		-	-	-	1,016
<b>Total Receipts / Income</b>		<b>70,463</b>	<b>35,228</b>	<b>105,691</b>	<b>78,468</b>
<b><u>Payments</u></b>					
Expenses for fundraising activities	8	3,210	-	3,210	2,534
Gross Trading Payments	8	3,918	-	3,918	-
Banking / Investment costs		96	-	96	78
Payments relating directly to charitable activities		-	-	-	-
Staff Costs	5	44,017	33,682	<b>77,699</b>	81,013
Administration & Office Costs	5	3,137	-	<b>3,137</b>	1,070
Insurances & Licences	5	1,179	-	<b>1,179</b>	2,499
Equipment	5	48	-	<b>48</b>	27
Subscriptions & Entrance Fees	5	383	-	<b>383</b>	120
Publications	7	201	-	<b>201</b>	-
Events	9	36,572	8,166	<b>44,738</b>	9,432
Grants	10	500	-	<b>500</b>	162
Governance Costs	13	-	-	-	1,271
Trustee Expenses	6	-	-	-	-
<b>Total Expenditure / Payments</b>		<b>93,261</b>	<b>41,848</b>	<b>135,109</b>	<b>98,206</b>
Total Receipts		70,463	35,228	<b>105,691</b>	78,468
Total Payments		93,261	41,848	<b>135,109</b>	98,206
<b>Surplus / (Deficit) for the year</b>		<b>(22,798)</b>	<b>(6,620)</b>	<b>(29,418)</b>	<b>(19,738)</b>
Transfers between funds	12	-	-	-	-
<b>Surplus / (Deficit) for the year</b>		<b>(22,798)</b>	<b>(6,620)</b>	<b>(29,418)</b>	<b>(19,738)</b>

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 30<sup>th</sup> June 2022**

	£	£	£	£
	Unrestricted	Restricted	Total	Total
	Funds	Funds	2022	2021
<b><u>Fund Reconciliation</u></b>				
Cash at Bank & In Hand – Start of year	56,284.46	16,842.00	<b>73,126.46</b>	5,691.77
Surplus / (Deficit) for the year	(22,797.88)	(6,620.25)	<b>(29,418.13)</b>	(19,738.42)
Transfer of Assets from 1072573	-	-	-	87,173.11
<b>Cash at Bank &amp; In Hand – end of year</b>	<b>33,486.58</b>	<b>10,221.75</b>	<b>43,708.33</b>	<b>73,126.46</b>

**Bank & Cash Balances**

CAF Bank Account	<b>41,599.77</b>	68,553.63
PayPal Account	<b>2,108.56</b>	4,572.83
Cash in Hand	-	-
	<b>43,708.33</b>	<b>73,126.46</b>

**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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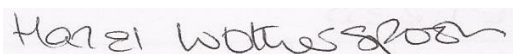
**Liabilities (Restricted Fund)**

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: 19<sup>th</sup> March 2023

## Notes to the Accounts – For the Year Ended 30<sup>th</sup> June 2022

### 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.

### 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 Received

The following grants were received in prior years and spent in 2021-2022: Spend £16.842

Grant	Provider	Purpose	Used for
£3,000	P F Charitable Trust	Core Costs	General salaries and overhead costs
£9,842	Pears Foundation (Contact)	Core Costs	General salaries and overhead costs
£3,000	P F Charitable Trust	Core Costs	General salaries and overhead costs
£1,000	Sir James Roll Trust	Core Costs	General salaries and overhead costs

The following grants were received during 2021-2022: (Total £35,228, of which £25,006 was spent in the year)

Grant	Provider	Purpose	Used for
£1,000	Arnold Clark	Unrestricted	General salaries and overhead costs
£2,000	The Hospital Saturday Fund	Information and Support Service core service and running costs	Salaries associated with delivery of support and development of web-based information
£3,702	Co-op Community	Community support	Support for families to attend regional and national events and associated staff support costs
£1,000	Albert Hunt	Information and Support Service	Salaries associated with delivery of support and development of web-based information
£2,500	Jeans for Genes	Core costs	General salaries and overhead costs
£3,686	Charities Trust (Nationwide Building Society)	Adult residential internship project	Carried forward to cover costs not yet incurred

Grant	Provider	Purpose	Used for
£10,000	C G Lawson Foundation	Unrestricted	General salaries and overhead costs
£2,500	Mercers Company	Conference costs	Family events (Conference)
£5,000	Foyle Foundation	Information and Support Service (not conference)	Carried forward
£2,500	Individual Donation	To help families attend conference	Family events: £1,964 spent and £536 carried forward for use in future years
£1,000	New Forest Business Club	Family small grants scheme	Carried forward for use in future years
£340	Jeans for Genes	Core costs	General salaries and overhead costs

The following grants / balances are held for use in future years: Total £10,222

Grant	Provider	Purpose
£3,686	Charities Trust (Nationwide Building Society)	Adult residential internship project
£536	Individual Donation	To help families attend conference
£1,000	New Forest Business Club	Family small grants scheme
£5,000	Foyle Foundation	Information and Support Service (not conference): Internship supervision for information research projects, and web-based guidance

## 5. Administration Costs

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

- Insurance premiums £253.
- Subscriptions to ACOSVO, Genetic Alliance UK and professional bodies £227.
- Entry fees for conferences and training £156.
- Small Lottery Licence and the Fundraising Regular Licence fees £70.
- Software licences £856.
- Membership CRM database subscription fees £1,318.
- Staff training, development, and strategy meetings £1,257.
- Office equipment £48.
- General stationery and postage costs £562.

### Staff Costs

Number of staff employed: 4 (1.4 to 1.7 FTE)  
 Period of employment: 1<sup>st</sup> July 2021 to 30<sup>th</sup> June 2022  
 Staff salaries including taxes and pensions: £77,699  
 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, except for a limited number of members.

£142 was spend on printed leaflets to raise awareness of SMS, and £59 on the purchase of reference books.

## **8. Fundraising**

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.

Donations are recorded as the basis of receiving of an altruistic gift either with a general charitable purpose or for the support of a project.

The Foundation received nine donations totalling £24,203 from various individuals and organisations with the highest single donation being for £2,700.

Income raised by the SMS community totalled £19,859. In memorial donations were £989.

Gross receipts from trading comprise sales of awareness merchandise through the charity's online shop of £1,762 and £300 from the delivery of SMS awareness sessions.

Expenses for fundraising activities relate to expenditure on fundraising merchandise and donation platform fees and subscriptions and totalled £3,210.

Expenditure relating to trading totalled £3,918 and comprised the cost of merchandise and postage and packing.

## **9. Events**

A four day in person conference was organised for families and professionals working with SMS.

Attendance and accommodation fees, and corporate support packages, raised £23,345.

The cost of the conference incurred during this financial year was £44,738. Total direct costs, excluding staff salaries, of the conference including deposits paid in previous years was £51,481.

## **10. Grants**

One grant to improve the life of a person with Smith-Magenis syndrome was awarded of £500 towards the cost of a specialist hydrotherapy bath.

## **11. Research**

No research was commissioned by the Foundation during the 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.