

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Registered UK Charity No: 1186647

Registered Scottish Charity (SCIO) No: SC050921

ACCOUNTS

30TH JUNE 2021

Registered Address:

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

Operating and Registered Address in Scotland:

Smith-Magenis Syndrome (SMS) Foundation UK
12 Bankton Brae
Livingston
West Lothian
EH54 9LA

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Contents of the Financial Statements

For the year ended 30th June 2021

	Page
Annual Report of the Trustees	3
Independent Examiner's Report	7
The Smith-Magenis Syndrome (SMS) Foundation UK CIO, 1186647 Receipts and Payments Account (General Purpose Fund)	9
Statement of Assets and Liabilities	10
Notes to the Accounts	11

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Annual Report of the Trustees for the year ended 30th June 2021

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 2021.

The Smith-Magenis Syndrome (SMS) Foundation UK CIO, 1186647, is a Charitable Incorporated Organisation. 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.

At an Extra-ordinary General Meeting (EGM) of the Smith-Magenis Syndrome (SMS) Foundation UK, charity no. 1072573 held on 16th November 2019 the membership voted in favour of transitioning the organisation from an unincorporated registered charity to a Charitable Incorporated Organisation (CIO). This vote held to the establishment and registration of the Smith-Magenis Syndrome (SMS) Foundation UK CIO. The transfer of all operational and financial matters was completed by 30th April 2021. The transitioning period has extended beyond 30th June 2021.

Reference & Administrative Information

Charity Name:	Charity Registration:
The Smith-Magenis Syndrome (SMS) Foundation UK	UK Registered Charity No 1072573 Registered Scottish Charity SC044841
The Smith-Magenis Syndrome (SMS) Foundation UK CIO	UK Registered Charity No 1186647 Registered Scottish Charity SC050921

Registered Address:

Smith-Magenis Syndrome (SMS) Foundation UK,
BCM Smith-Magenis Syndrome Foundation, London, WC1N 3XX

Operating Address:

Smith-Magenis Syndrome (SMS) Foundation UK,
12 Bankton Brae, Livingston, West Lothian, EH54 9LA

Current Trustees:

The Charity is administered as a single operating entity, "The Foundation", by a management committee, comprising:

Name	Elected	Resigned
Hazel Wotherspoon (Chairperson) *	16/11/2019	
Nick Hunt *	16/11/2019	
Emma Riddell *	16/11/2019	
Mick Pearson *	16/11/2019	
Laura Maddocks	12/01/2021	
Wendy Ferguson	12/01/2021	

* These Trustees also comprise the management committee of the Smith-Magenis Syndrome (SMS) Foundation UK, UK Charity No 1072573 and Scottish Charity SC044841.

Three individuals have been co-opted as non-trustee members of the board and are Peter Scott, Rosina Mosedale, and Jayne Dainty.

Structure Governance & Management

Constitution:

The Smith-Magenis Syndrome (SMS) Foundation UK CIO, 1186647, is a Charitable Incorporated Organisation. 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.

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 **The Smith-Magenis Syndrome (SMS) Foundation UK CIO**, 1186647, states that there must be no less 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.

On 1st April 2020 a Senior Management Team was employed to run the day-to-day operations of the Smith-Magenis Syndrome (SMS) Foundation UK CIO. The Management team comprises:

Chief Executive Officer:	Nigel Over
Information & Communications Manager:	Leeann Stevenson
Fundraising Manager:	Helen Hargrave

Objectives & Activities

Charitable Purposes:

The charities' 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.

Achievements & Performance:

During the reporting period, the Foundation continued to deliver activities to meet the objects of the charities, and particularly:

- The Foundation has 613 registered supporters (up from 534), an increase of 15% over the course of this year. These comprise 424 UK family members, 97 international families, 59 UK professionals, and 33 international professionals.
- 526 UK individuals are now known to have been diagnosed with Smith-Magenis syndrome following the completion of our UK Demographics Study in September 2020 (up from 302).
- 287 Easter cards were sent to the UK SMS individuals registered with us, followed by 259 Teddy Bear picnic boxes (40 supplied in 2020).
- 139 hours of online community cohesion support was provided through 99 virtual videoconferencing sessions.

- Virtual community events have included:
 - In the home activities as a series of Bear Hug and Be Hugged themed events
 - SMS Christmas Card competition
 - December advent calendar activities
 - Easter Cards for every person with SMS
 - Teddy Bears Picnic 2021
 - Stay Awake Challenge 2021
- 119 enquiries were received with over 200 hours spend by the management and trustees in responding to the matters raised. 99.2% of enquiries were responded to within 2-3 days.
- Smith-Magenis syndrome information through our revamped website is available in English, German, Portuguese and Italian.
- Responded to Covid-19 with focussed information and support through community cohesion initiatives including:
 - Syndrome emergency packs, Alert ID Cards, space identifiers, etc.,
 - Greater social media presence, website enhancements and regular newsletters,
 - Wellbeing blogs,
 - The launch of Spotlight on SMS with a feature on sleep.
- The 2021 conference was unable to go ahead in May due to Covid-19 restrictions. All plans and bookings have been carried forward to April/May 2022.
- Launched our Regional Parent Support (RePS) initiative, with 16 volunteers recruited.
- Actively raised the profile of the Foundation through fundraising and awareness campaigns.
- Created our online shop for awareness merchandise.
- Building networks with genetic and third sector organisations. Presentations have been delivered to Genetic Alliance UK, the international SMS professional community, University internship teams, and poster participation at RareFEST2021.
- Patient group submissions and involvement made to MHRA, NICE, SMC, AWMSCG.
- Awards and Recognition
 - SCVO Charity Award Winner 2020
 - Highly commended in Breaking Barriers Awards 2020
 - NUE Charity Awards Finalist 2020
- Two small grants were awarded to Improve the lives of people with Smith-Magenis Syndrome through the £500 maximum individual small grants scheme.
- Commenced the implementation of the business development strategy for the growth of the charity over the next 1, 3, 5 and 10 years.
- Reviewed and developed our overarching digital strategy.
- Hosted seven students on projects including two from the University of Keele on the UK Demographics Study, and five from Edinburgh Napier University on the safe sleeping teddy bear animation awareness project.
- Recruited a Research and Admin Assistant from the student internship programme to support the Senior Management Team.

Financial Review

Extensive efforts were made to raise funds and support for the Foundation throughout the year. £78,468 was raised this year. £51,633 came from grants. £26,835 through charitable donations and general fundraising activities. £70,135 was received as an asset transfer from The Smith-Magenis Syndrome (SMS) Foundation UK, charity number 107 2573 (Scottish Charity SC044841)

Expenditure for the year totalled £98,206. Significant expenditure in 2020-21 was made to support the transition of the Foundation to a staffed Charitable Incorporated Organisation.

- £81,013 was spent on staff costs, used to deliver our charitable activities.
- £3,794 in connection with running of the charity and fulfilling the statutory duties.
- £2,534 for Fundraising materials and subscriptions. Expense has been incurred for enhanced fundraising platform subscriptions, promotional materials, merchandising items, and event entries.
- £9,432 has been spent on events, the majority being for deposits connected to the next conference.
- £162 for grants to improve the life of a person with Smith-Magenis.
- £1,271 on costs directly related to our strategic development activities.

Money assets at the year end of 30 June 2021 was £73,126 for which £13,842 is restricted funding for the staff costs in England and Wales.

Reserves Policy

From 1st April 2020, the Foundation has moved to a staffed organisation necessitating the implementation of a reserves policy and strategy. It is the intention of the Foundation to seek to retain a minimum of twelve months of core operating expenditure as the basis of its cash reserves, excluding restricted funding for projects. However, in light of Covid-19 and the move to employing staff members, the Board's position is that the Foundation should maintain six months of reserves as a reasonable position under current circumstances. Should unrestricted reserves drop to three months of core operating costs then contingency measures would be implemented to lower planned expenditure to sustain the charity for at least one year.

Plans for Future Periods

During the next financial year, the Foundation intends to continue to deliver activities to meet the objects of the charity, with specific objectives to:

Connecting Families

- provide continuing community cohesion activities including videoconferencing and home orientated activities,
- promote social gatherings and meetings to connect families together, with the assistance of our Regional Parent Supporter network,
- launch the Genny Bear Relay to link local families together,
- organise a conference for April – May 2022.

Raising Awareness

- continue to develop networks for mutual support with charities of a similar nature and establish applicable alliances, both in the United Kingdom and internationally,
- to actively raise the profile of the Foundation through fundraising and awareness campaigns,
- develop and produce education and information videos and guidelines to assist those supporting people with Smith-Magenis Syndrome,

Building Futures

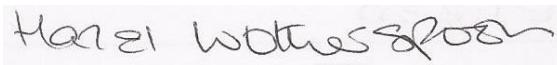
- provide an information and support services for families and professionals,
- refine our published information and guidance incorporating advances in the research and understanding of Smith-Magenis syndrome,
- conclude research into sleep safety and security within Smith-Magenis Syndrome,
- develop a programme of continuing research,

- improve the lives of people with Smith-Magenis Syndrome through the individual small grants scheme,

Sustainability

- complete the transition to the Charitable Incorporated Organisation,
- continue with the business development strategy for the growth of the charity over the coming years,
- implement the overarching digital strategy, commencing with the establishment of an operational database platform for membership and engagement,
- develop the organisational structure to deliver our strategic objectives effectively and efficiently,
- deliver on a fundraising strategy to grow the charity in line with these development plans.

Approved by the trustees and signed on their behalf by:



Hazel Wotherspoon – Chairperson

Date: 14th December 2021

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Independent Examiner's Report to the Trustees of
THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO
For the year ended 30th June 2021

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 2020 to 30th June 2021
Charity Registration: Registered UK Charity 1186647
Set out on pages: Pages 10 and 11

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: 14 / 12 / 2021

Name: Mark Middleton

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

Address: 1 Vicarage Lane, London, E15 4HF

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

Accounts for the period 1st July 2020 to 30th June 2021

Statement of Receipts and Payments Account (General Purpose Fund)

Receipts and Payments Account: General Fund

	Note	£ Unrestricted Funds	£ Restricted Funds	£ Total 2021	£ Total 2020
<u>Receipts</u>					
<u>Voluntary Sources</u>					
Donations and membership fees	8	2,285.64	-	2,285.64	1,702.76
Legacies		115.00	-	115.00	-
Grants	4	-	51,633.00	51,633.00	3,000.00
Receipts from fundraising activities	8	22,638.68	-	22,638.68	8,684.86
Gross receipts from trading		329.42	-	329.42	-
Organised Event Income	9	450.00	-	450.00	-
Gross Receipts from other activity		1,016.33	-	1,016.33	-
Total Receipts / Income		26,835.07	51,633.00	78,468.07	13,387.62
<u>Payments</u>					
Expenses for fundraising activities	8	2,533.83	-	2,533.83	2,347.60
Banking / Investment costs		78.00	-	78.00	-
Payments relating directly to charitable activities	4,5,7,11	-	-	-	4,803.01
Staff Costs		48,596.91	32,416.00	81,012.91	-
Administration & Office Costs		1,070.46	-	1,070.46	-
Insurances & Licences		2,499.01	-	2,499.01	-
Equipment		26.74	-	26.74	-
Subscriptions		120.00	-	120.00	-
Events	9	4,057.49	5,375.00	9,432.49	-
Grants	10	161.78	-	161.78	500.00
Governance Costs	13	1,271.27	-	1,271.27	-
Trustee Expenses	6	-	-	-	45.24
Total Expenditure / Payments		60,415.49	37,791.00	98,206.49	7,695.85
Total Receipts		26,835.07	51,633.00	78,468.07	13,387.62
Total Payments		60,415.49	37,791.00	98,206.49	7,695.85
Surplus / (Deficit) for the year		(33,580.42)	13,842.00	(19,738.42)	5,691.77
Transfers between funds	12	-	-	-	-
Surplus / (Deficit) for the year		(33,580.42)	13,842.00	(19,738.42)	5,691.77

The Notes on pages 11 and 12 form an integral part of these accounts.

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Statement of Balances on Assets and Liabilities as of 30th June 2021

	£ Unrestricted Funds	£ Restricted Funds	£ Total 2021	£ Total 2020
<u>Fund Reconciliation</u>				
Cash at Bank & In Hand – Start of year	2,691.77	3,000.00	5,691.77	-
Surplus / (Deficit) for the year	(33,580.42)	13,842.00	(19,738.42)	5,691.77
Transfer of Assets from 1072573	87,173.11	-	87,173.11	-
Cash at Bank & In Hand – end of year	56,284.46	16,842.00	73,126.46	5,691.77

Bank & Cash Balances

The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647)

CAF Bank Account	68,553.63	5,125.66
PayPal Account	4,572.83	566.11
Cash in Hand	-	-
	73,126.46	5,691.77

Other Assets (Unrestricted Fund)

There are no other assets

- -

Liabilities (Unrestricted Fund)

No current unrestricted fund liabilities

- -

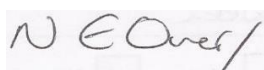
Liabilities (Restricted Fund)

Information and Support Service

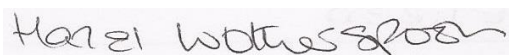
	Total Value	20/21 Due	19/20 Paid
	3,000.00	3,000.00	-
	3,000.00	3,000.00	-

The Notes on pages 11 and 12 form an integral part of these accounts.

Approved by the Trustees and signed on their behalf by:



Nigel Over (Chief Executive Officer)



Hazel Wotherspoon (Chairperson)

Date: 14th December 2021

Notes to the Accounts – For the Year Ended 30th June 2021

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 during 2019-2020 for use in 2020-2021:

Trust or Fund	Value	Purpose
P F Foundation	£3,000	Information & Support Service

The following grants were received during 2020-2021:

Trust or Fund	Value	Purpose
Tesco / Groundwork UK	£500	Community Event
Neighbourly Community Fund	£400	
NLF Covid-19 Response	£9,437	Salary costs
Catalyst Digital Grant	£5,000	Digital Discovery Project
Pears Foundation (Contact)	£8,194	Regional support programme
Hugh Fraser Foundation	£2,000	Core costs
The Baily Thomas Foundation	£1,000	Information Service
Catalyst Digital Grant	£5,000	Digital Definition Project
Catalyst Digital Grant	£5,000	Digital Continuation Project
P F Charitable Trust	£3,000	Core costs
Sir James Roll Trust	£1,000	Core costs
University of Keele	£1,260	Student Employability Plan

The following grants were received during 2020-2021 for use in 2021-2022:

Trust or Fund	Value	Purpose
Pears Foundation (Contact)	£9,842	Core costs – salaries

5. Administration

All costs associated with consumed stationery, newsletter printing, correspondence, website hosting fees, virtual office fees, and insurance premiums have been combined under this heading.

- Insurance premiums this year were £1,487
- Subscriptions to ACOSVO and Genetic Alliance UK totalled £120.
- Small Lottery Licence and the Fundraising Regular incurred fees of £90
- £922 was spend on software for Zoom and Adobe Suite

- Monthly bank fees totalled £78
- General stationery and mail service costs were £1,097 for the year.

Staff Employed

Number of staff employed:	4 (1.4 to 1.7 FTE)
Period of employment:	1 st July 2020 to 30 th June 2021
Staff salaries including taxes and pensions:	£81,013

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 nor legal fees were incurred during 2020-21.

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.

No costs were incurred to support the production and distribution of the publications.

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.

Expenditure on fundraising merchandise, platform fees and subscriptions, totalled £2,534.

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 £2,286 from various individuals and organisations with the highest single donation being for £600.

Income raised by the Smith-Magenis syndrome community totalled £22,639. In memorial donations were £115.

Sales of awareness merchandise through the charity's online shop were worth £329.

Other income includes £40 for the refund of the small lotteries licence on change of registered address, and £976 from Enkay Digital Limited for the participation of the Chief Executive Officer in their digital focus workshops.

9. Events

A virtual Teddy Bears' Picnic was organised with material costs amounting to £5,220. A refund of £450 was received from a supplier in connection to the 2021 Teddy Bears' Picnic and is recorded under income from events. Staff costs associated with the event are reported under charity administration.

A deposit of £4,213 has been paid to Kew Green Hotels to secure the venue for our next conference.

10. Grants

Grants to improve the life of persons with Smith-Magenis syndrome totalled £162 and included:

- £126 towards the costs of a car seat travel harness,
- £36 commemoration flowers.

11. Research

No research has been commissioned by The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647 / SC050921) during this reporting period.

12. Transfers between funds

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

As part of the transition to the Charitable Incorporated Organisation, assets totalling £70,135 being to The Smith-Magenis Syndrome (SMS) Foundation UK (1072573 / SC044841) have been transferred to The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647 / SC050921).

13. Governance Costs

£1,272 was spend on a strategy day in October 2020.