

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Registered UK Charity No: 1072573
Registered Scottish Charity No: SC044841

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Registered UK Charity No: 1186647

Annual Report to Members

30TH JUNE 2020

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

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

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

Annual Report of the Trustees for the year ended 30th June 2020

The Trustees have pleasure in presenting their report together with the financial statements for the year ended 30 June 2020.

To satisfy regulatory requirements, separate financial accounts are required to be submitted to the Charity Regulators. These accounts are independently examined with the report provided relevant to the financial status of each charity entity.

Although the charities exist as two separate legal entities, the Trustees consider that it is appropriate to report to members on the performance of both charities together given their interconnectivity.

At an Extra-ordinary General Meeting held on 16 November 2019 the membership voted in favour of transitioning the organisation from an unincorporated registered charity to a Charitable Incorporated Organisation (CIO). The transitioning period has extended beyond 30 June 2020. This Annual Report of the Trustees seeks to provide a statement of the financial operations pertinent to running of the Foundation, with individual account submissions for the two registered charitable organisations.

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 Address:

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

Operating and Registered Address in Scotland:

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

Current Trustees:

The Charities are administered as a single operating entity, "The Foundation", by a management committee, comprising:

Name	Charity 1072573	Charity 1186647	
Hazel Wotherspoon (Chairperson)	Re-elected 30/04/2017	Elected 16/11/2019	
Nick Hunt	Re-elected 05/05/2019	Elected 16/11/2019	
Nigel Over	Re-elected 05/05/2018	Elected 16/11/2019	Resigned 31/03/2020
Leeann Stevenson	Re-elected 05/05/2018	Elected 16/11/2019	Resigned 31/03/2020
Emma Riddell	Re-elected 30/04/2017	Elected 16/11/2019	
Mick Pearson	Elected 05/05/2018	Elected 16/11/2019	

Structure Governance & Management

Constitution:

The Smith-Magenis Syndrome (SMS) Foundation UK, 1072573, is an unincorporated association. It is governed by its constitution which was adopted on 21 March 1998 and last amended on 02 June 2013. The Smith-Magenis Syndrome (SMS) Foundation UK became registered with the Charities Commission on 24 November 1998 and the Office of the Scottish Charity Regulator on 01 May 2014.

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 16 November 2019. The Smith-Magenis Syndrome (SMS) Foundation UK CIO became registered with the Charities Commission on 28 November 2019.

Appointment of Trustees:

Under both constitutions 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**, 1072573, states that there must be no less than three trustees and no more than nine trustees. Up to six trustees are elected from the membership of the charity with provision for the appointment of further trustees. At the EGM of 16 November 2019, the resolution was adopted for the legal membership of the charity to be reduced to the elected Trustees.

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 01 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:

- held member events,
- the Foundation has 534 registered supporters and has identified 302 individuals in the UK who have a diagnosis of Smith-Magenis Syndrome,
- attended the International SMS Research Symposium in Texas, USA, presenting on our research projects,
- actively raised the profile of the Foundation through fundraising and awareness campaigns,
- promoted further collaboration in research into Smith-Magenis Syndrome, particularly on the sleep safety research project,
- improved the lives of people with Smith-Magenis Syndrome through the £500 maximum individual small grants scheme,
- responded to Covid-19 with focussed information and support through community cohesion initiatives including:
 - Syndrome emergency packs and Alert ID Cards,
 - Videoconferencing community drop-in support sessions,
 - In the home activities as a series of Bear Hug and Be Hugged themed events,
 - Greater social media presence, website enhancements and regular newsletters,
- Completion of the initial governance review and formulation of the business development strategy for the growth of the charity over the next 1, 3, 5 and 10 years,
- Recruited the Senior Management Team to run the Foundation.

Financial Review

The Trustees continued to make extensive efforts to raise funds and support for the Foundation throughout the year. £39,643 was raised this year through charitable donations and general fundraising activities as a result of the tireless efforts of our Trustees and supporters. Further income of £26,778 has come in the form of Trusts and Funds Grants towards the development of our Information / Support Service and Covid-19 response initiatives. This gives a combined income of £66,421 for the Foundation over the financial year.

Significant expenditure in 2019-20 was made to support the transition of the Foundation to a staffed Charitable Incorporated Organisation.

- £16,106 was spent on consultancy services for the governance review and production of the Business Development Strategy.
- £14,599 was spent in connection with Fundraising activities. This included the costs associated with the recruitment of the Fundraising Manager. £4,800 of unrestricted reserves was spent on the services of a Trusts and Funds Associate, although the changed profile of grant giving due to Covid-19 has meant that this has yielded a return of £4,000 as restricted income. Expense has also been incurred for enhanced fundraising platform subscriptions, promotional materials including the mascot costume, merchandising items, and event entries.
- £6,741 was spent on the Safe Sleeping research project.
- £18,734 has been spent on the running of the Foundation with staff salaries accounting for £14,938 of this amount.
- Grants to improve the life of persons with Smith-Magenis syndrome totalled £2,479 and included equipment funding for tricycles, TV protection, and wheelchairs.

Money assets at the year end of 30 June 2020 was £75,827 for which £15,795 is restricted funding for Covid-19 activities and the Information and Support Service.

Reserves Policy

The Foundation has traditionally maintained a prudent financial position of not committing to any expenditure unless the full costs could be covered from reserves. Planned expenditure would be agreed at the start of the financial year based on the value of cash assets held at the end of the previous financial year. With low yearly operating costs, and without project expenditure, the reserves were sufficient to meet the ongoing running costs of the Foundation for several years.

From 01 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 Covid-19 community cohesion activities including videoconferencing and home orientated activities,
- promote social gatherings and meetings to connect families together,
- establish a regional support network for families,
- organise the biennial conference for May 2021

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,

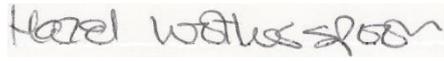
Building Futures

- provide an information and support services for families and professionals,
- conclude research into sleep safety and security within Smith-Magenis Syndrome,
- undertake a demographics study to establish a more definitive understanding of the prevalence and geographical location of Smith-Magenis syndrome in the UK,
- develop a programme of continuing research,
- commission research into behaviour improvement utilising vagus nerve stimulation,
- 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,
- develop the organisational structure to deliver our strategic objectives effectively and efficiently.

Approved by the trustees and signed on their behalf by:

A handwritten signature in black ink that reads "Hazel Wotherspoon". The signature is written in a cursive style and is positioned above a horizontal line.

Hazel Wotherspoon – Chairperson

Date: 12 January 2021

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

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

Combined Operating Accounts for the year to 30th June 2020

Statement of Receipts and Payments Account

Receipts and Payments Account

<u>Receipts</u>	Note	£ Unrestricted Funds	£ Restricted Funds	£ Total 2020	£ Total 2019
<u>Voluntary Sources</u>					
Donations and membership fees	8	4,796.35	-	4,796.35	16,386.68
Grants	4	-	26,778.00	26,778.00	4,890.00
Receipts from fundraising activities	8	34,847.11	-	34,847.11	27,124.35
Organised Event Income	9	-	-	-	23,999.62
Total Receipts / Income		39,643.46	26,778.00	66,421.46	72,399.65
<u>Payments</u>					
Expenses for fundraising activities	8	14,598.64	-	14,598.64	3,661.97
Payments relating directly to charitable activities	4,5,7,11	14,540.30	10,983.00	25,523.30	11,202.50
Events	9	3,153.62	-	3,153.62	48,107.76
Grants	10	2,478.94	-	2,478.94	1,261.00
Governance Costs	13	14,075.76	-	14,075.76	8,970.00
Trustee Expenses	6	2,075.72	-	2,075.72	538.76
Total Expenditure / Payments		50,922.98	10,983.00	61,905.98	73,741.99
Total Receipts		39,643.46	26,778.00	66,421.46	72,399.65
Total Payments		50,922.98	10,983.00	61,905.98	73,741.99
Surplus / (Deficit) for the year		(11,279.52)	15,795.00	4,515.48	(1,342.34)
Transfers between funds	12	-	-	-	-
Surplus / (Deficit) for the year		(11,279.52)	15,795.00	4,515.48	(1,342.34)

Bank & Cash Balances

	<u>30/06/20</u>	<u>30/06/19</u>
Barclays Bank Current Account (1072573)	1,841.74	69,355.40
PayPal Account (1072573)	4,018.27	1,955.90
CAF Bank Account (1072573 & 1186647)	69,400.66	-
PayPal Account (1186647)	566.11	-
Cash in Hand	-	-
	75,826.78	71,311.30

The Notes on pages 12 to 14 form an integral part of these accounts.

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK, 1072573 / SC044841

Accounts for the year 1st July 2019 to 30th June 2020

Statement of Receipts and Payments Account (General Purpose Fund)

Receipts and Payments Account: General Fund

		£	£	£	£
		Unrestricted	Restricted	Total	Total
<u>Receipts</u>	<u>Note</u>	<u>Funds</u>	<u>Funds</u>	<u>2020</u>	<u>2019</u>
<u>Voluntary Sources</u>					
Donations and membership fees	8	3,093.59	-	3,093.59	16,386.68
Grants	4	-	23,778.00	23,778.00	4,890.00
Receipts from fundraising activities	8	26,162.25	-	26,162.25	27,124.35
Organised Event Income	9	-	-	-	23,999.62
Total Receipts / Income		29,255.84	23,778.00	53,033.84	72,399.65
<u>Payments</u>					
Expenses for fundraising activities	8	12,251.04	-	12,251.04	3,661.97
Payments relating directly to charitable activities	4,5,7,11	9,737.29	10,983.00	20,720.29	11,202.50
Events	9	3,153.62	-	3,153.62	48,107.76
Grants	10	1,978.94	-	1,978.94	1,261.00
Governance Costs	13	14,075.76	-	14,075.76	8,970.00
Trustee Expenses	6	2,030.48	-	2,030.48	538.76
Total Expenditure / Payments		43,227.13	10,983.00	54,210.13	73,741.99
Total Receipts		29,255.84	23,778.00	53,033.84	72,399.65
Total Payments		43,227.13	10,983.00	54,210.13	73,741.99
Surplus / (Deficit) for the year		(13,971.29)	12,795.00	(1,176.29)	(1,342.34)
Transfers between funds	12	-	-	-	-
Surplus / (Deficit) for the year		(13,971.29)	12,795.00	(1,176.29)	(1,342.34)

The Notes on pages 12 to 14 form an integral part of these accounts.

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

Accounts for the period 28th November 2019 to 30th June 2020

Statement of Receipts and Payments Account (General Purpose Fund)

Receipts and Payments Account: General Fund

		£	£	£	£
		Unrestricted	Restricted	Total	Total
Receipts	Note	Funds	Funds	2020	2019
Voluntary Sources					
Donations and membership fees	8	1,702.76	-	1,702.76	-
Grants	4	-	3,000.00	3,000.00	-
Receipts from fundraising activities	8	8,684.86	-	8,684.86	-
Organised Event Income	9	-	-	-	-
Total Receipts / Income		10,387.62	3,000.00	13,387.62	-
Payments					
Expenses for fundraising activities	8	2,347.60	-	2,347.60	-
Payments relating directly to charitable activities	4,5,7,11	4,803.01	-	4,803.01	-
Events	9	-	-	-	-
Grants	10	500.00	-	500.00	-
Governance Costs	13	-	-	-	-
Trustee Expenses	6	45.24	-	45.24	-
Total Expenditure / Payments		7,695.85	-	7,695.85	-
Total Receipts		10,387.62	3,000.00	13,387.62	-
Total Payments		7,695.85	-	7,695.85	-
Surplus / (Deficit) for the year		2,691.77	3,000.00	5,691.77	-
Transfers between funds	12	-	-	-	-
Surplus / (Deficit) for the year		2,691.77	3,000.00	5,691.77	-

The Notes on pages 12 to 14 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 2020

	£	£	£	£
	Unrestricted	Restricted	Total	Total
<u>Fund Reconciliation</u>	Funds	Funds	2020	2019
Cash at Bank & In Hand – Start of year	71,311.30	-	71,311.30	72,653.64
Surplus / (Deficit) for the year	(11,279.54)	15,795.00	4,515.46	(1,342.34)
Cash at Bank & In Hand – end of year	60,031.76	15,795.00	75,826.78	71,311.30

Bank & Cash Balances

	30/06/2020	30/06/2019
The Smith-Magenis Syndrome (SMS) Foundation UK (1072573 / SC044841)		
Barclays Bank Current Account (1072573)	1,841.74	69,355.40
CAF Bank Account (1072573, part of)	64,275.00	-
PayPal Account (1072573)	4,018.27	1,955.90
Cash in Hand	-	-
	70,135.01	71,311.30
The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647)		
CAF Bank Account (1186647, part of)	5,125.66	-
PayPal Account (1186647)	566.11	-
Cash in Hand	-	-
	5,691.77	-
Total Combined Balances	75,826.78	71,311.30

Other Assets (Unrestricted Fund)

There are no other assets	-	-
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Liabilities (Unrestricted Fund)

	Total Value	20/21 Due	19/20 Paid
Sleep Safety Research Project (Note 11)	15,590.00	3,790.00	11,800.00
	15,590.00	3,790.00	11,800.00

Liabilities (Restricted Fund)

	Total Value	20/21 Due	19/20 Paid
Information and Support Service	7,841.00	3,000.00	4,841.00
Covid-19 Community Cohesion Projects	5,578.00	2,507.00	3,071.00
Covid-19 Wellbeing Fund (Salaries)	13,359.00	10,288.00	3,071.00
	26,778.00	15,795.00	10,983.00

The Notes on pages 12 to 14 form an integral part of these accounts.

Notes to the Accounts – For the Year Ended 30 June 2020

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 unrestricted 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 no restricted funding.

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:

Trust or Fund	Value	Purpose	Period Covered
P F Foundation	£3,000	Information and Support Service	Jun-Dec 2020
National Lottery Community Fund	£7,912	Covid-19 Community Cohesion: Zoom videoconferencing, and Information and Support Service	Apr-Jun 2020
Foundation Scotland	£2,507	Covid-19 Community Cohesion: Enhanced videoconferencing	May-Jul 2020
Wellbeing Fund	£13,359	Covid-19 response: Staff salary and IT workstation	May-Aug 2020

£4,800 of unrestricted reserves was spent on the services of a Trusts and Funds Associate, although the changed profile of grant giving due to Covid-19 has meant that this has yielded a return of £4,000 as restricted income. This comprises the grant from the P F Foundation and a pledge of £1,000 from the Baily Thomas Foundation Trust.

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.

Staff Employed

Number of staff employed:	3 (1.4 to 1.7 FTE)
Period of employment:	From 01 April 2020
Staff salaries including taxes and pensions:	£14,938

No member of staff has a salary above £60,000 p.a.

6. Trustee Expenses

Trustees claimed expenses totalling £2,075.72 during the period for reimbursement of general travelling costs and subsistence relating to activities of the charity, including the strategy development weekend and attendance at the Extraordinary General Meeting.

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 2019-20.

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.

Costs of £48 were incurred to support the production and distribution of the publications.

8. Fundraising

£4,800 of unrestricted reserves was spent on the services of a Trusts and Funds Associate, although the changed profile of grant giving due to Covid-19 has meant that this has yielded a return of £4,000 as restricted income. This comprises the grant from the P F Foundation and a pledge of £1,000 from the Baily Thomas Foundation Trust.

Expenditure directly relating to the recruitment of the Fundraising Manager totalled £6,620.

Subscriptions to the Fundraising Regulator and one fundraising platform incurred a cost of £290.

Fundraising costs of £870 were incurred in connection with the securing of places in the London Vitality Half Marathon and the Great North Run. No charges for places were made. Participants sought individual donations and sponsorship, and these are recorded under fundraising income.

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.

General merchandising items cost £2,029 which includes £450 for the Foundation's mascot.

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 two donations of £250 and £1,000 from Flynn Pharma Ltd.

The Foundation was successful in becoming a charity partner for Jeans for Genes and the Co-op Community Fund. A small amount was paid to the Foundation through online downloading of our Guide to Smith-Magenis Syndrome. These are recorded under fundraising income.

9. Events

Two events for members were organised during 2019-20:

- An event for members in Scotland took place in September 2019 at a cost of £104.
- A combined Extraordinary General Meeting and social event took place in South England in November at a cost of £355.

The biennial conference took place over the weekend of 3-6 May 2019. Residual payments of £164 were made with respect to speaker expenses.

Deposits of £2,531 have been paid with respect to the 2021 conference scheduled to take place from 30 April to 03 May 2021.

10. Grants

Grants to improve the life of persons with Smith-Magenis syndrome totalled £2,479 and included:

- £1,000 towards the cost of a specialist wheelchairs,
- £451 and £500 towards the costs of two tricycles
- £500 towards the cost of enclosing and protecting a television screen,
- £28 for flowers.

11. Research

A research project on Sleep Safety in Smith-Magenis syndrome commenced in 2018-19 with the University of Birmingham with a total project cost of £15,590. An interim payment was made this year of £5,900, leaving a balance due of £3,790.

The Foundation also covered the £563 costs for the lead researcher to attend the SMS Research Symposium held in Texas, USA to present on this project.

12. Transfers between funds

As part of the transition to the Charitable Incorporated Organisation, the assets of The Smith-Magenis Syndrome (SMS) Foundation UK (1072573 / SC044841) will be transferred to The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647).

The CAF Bank Account will be the principal account for receipt of new funding and transfer of assets.

13. Governance Costs

The trustees commissioned Bruce Tait Associates as consultants to assist with the development and growth strategy of the charity. The total cost of the consultancy is £22,200. The balance of £13,230 was paid in 2019-20.

Costs of £846 were incurred for venue charges for the Board Development Weekend in September 2019.