

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Registered UK Charity No: 1186647

ACCOUNTS

30TH JUNE 2020

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

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

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THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

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

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

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.

At an Extra-ordinary General Meeting (EGM) of the Smith-Magenis Syndrome (SMS) Foundation UK, charity no. 1072573 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). This vote held to the establishment and registration of the Smith-Magenis Syndrome (SMS) Foundation UK CIO. The transitioning period has extended beyond 30 June 2020.

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 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	
Nigel Over	16/11/2019	31/03/2020
Leeann Stevenson	16/11/2019	31/03/2020
Emma Riddell	16/11/2019	
Mick Pearson	16/11/2019	

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

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

- the Foundation has 534 registered supporters and has identified 302 individuals in the UK who have a diagnosis of Smith-Magenis Syndrome,
- actively raised the profile of the Foundation through fundraising and awareness campaigns,
- promoted further collaboration in research into Smith-Magenis Syndrome,
- 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,
- Commenced the implementation 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. £10,388 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 £3,000 has come in the form of Trusts and Funds Grants towards the development of our Information / Support Service. This gives a combined income of £13,388 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.

- £2,348 was spent in connection with Fundraising activities. Expense has been incurred for enhanced fundraising platform subscriptions, promotional materials including the mascot costume, merchandising items, and event entries.
- £4,848 has been spent on the running of the Foundation with staff salaries accounting for £3,955 of this amount.
- One grant to improve the life of a person with Smith-Magenis syndrome of £500 was provided towards the cost of a specialist tricycle.

Money assets at the year end of 30 June 2020 was £5,692 for which £3,000 is restricted funding for the Information and Support Service.

Reserves Policy

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:



Hazel Wotherspoon – Chairperson

Date: 12 January 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 30 June 2020

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: 28 November 2019 to 30 June 2020
Charity Registration: Registered UK Charity 1186647
Set out on pages: Pages 9 and 10

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: 12 January 2021

Name: Mark Middleton

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

Address: 1 Vicarage Lane, E15 4HF

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

	Note	£ Unrestricted Funds	£ Restricted Funds	£ Total 2020	£ Total 2019
Receipts					
<u>Voluntary Sources</u>					
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 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 2020

	£	£	£	£
	Unrestricted	Restricted	Total	Total
<u>Fund Reconciliation</u>	Funds	Funds	2020	2019
Cash at Bank & In Hand – Start of year	-	-	-	-
Surplus / (Deficit) for the year	2,691.77	3,000.00	5,691.77	-
Cash at Bank & In Hand – end of year	2,691.77	3,000.00	5,691.77	-

Bank & Cash Balances

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	-	-
	5,691.75	-

Other Assets (Unrestricted Fund)

There are no other assets

Liabilities (Unrestricted Fund)

No current unrestricted fund liabilities

Liabilities (Restricted Fund)

	Total Value	20/21 Due	19/20 Paid
Information and Support Service	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

Nigel Over

Hazel Wotherspoon

Hazel Wotherspoon (Chairperson)

Date: 12 January 2021

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

A pledge of £1,000 from the Baily Thomas Foundation Trust has been given.

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:	£3,955

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

6. Trustee Expenses

Trustees claimed expenses totalling £45 during the period for reimbursement of general travelling costs and subsistence relating to activities of the charity.

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.

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

8. Fundraising

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

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 £2,058 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 one donation of £1,000 from Flynn Pharma Ltd.

9. Events

No events have taken place in the reporting period that have incurred any costs nor generated any income.

10. Grants

Grants to improve the life of persons with Smith-Magenis syndrome totalled £500 and included:

- £500 towards the costs of a specialist tricycle

11. Research

No research has been commissioned by The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647) 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, the assets from The Smith-Magenis Syndrome (SMS) Foundation UK (1072573 / SC044841) will be transferred to The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647).

13. Governance Costs

No costs relating to the governance of The Smith-Magenis Syndrome (SMS) Foundation UK CIO have been incurred within the accounting period.