

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

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

**ACCOUNTS**

**30<sup>TH</sup> JUNE 2020**

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

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

**Contents of the Financial Statements**

**For the year ended 30<sup>th</sup> June 2020**

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

### **Annual Report of the Trustees for the year ended 30<sup>th</sup> 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.

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). All existing assets of the Smith-Magenis Syndrome (SMS) Foundation UK are being transferred to the new charity, The Smith-Magenis Syndrome (SMS) Foundation UK CIO. The transitioning period has extended beyond 30 June 2020.

#### **Reference & Administrative Information**

<b>Charity Name:</b>	<b>Charity Registration:</b>
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 Charity is administered by a management committee, comprising:

<b>Name</b>	<b>Appointments</b>	<b>Resignations</b>
Hazel Wotherspoon (Chairperson)	Re-elected 30/04/2017	
Nick Hunt	Re-elected 05/05/2019	
Nigel Over	Re-elected 05/05/2018	Resigned 31/03/2020
Leeann Stevenson	Re-elected 05/05/2018	Resigned 31/03/2020
Emma Riddell	Re-elected 30/04/2017	
Mick Pearson	Elected 05/05/2018	

#### **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.

##### **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**, 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.

#### **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 appointed to run the day-to-day operations of the charity. 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,
- 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 Smith-Magenis Syndrome (SMS) Foundation UK CIO, registered charity number 1186647.

#### **Financial Review**

The Trustees continued to make extensive efforts to raise funds and support for the Foundation throughout the year. £53,034 was raised this year, £23,778 has come in the form of Trusts and Funds

Grants towards the development of our Information / Support Service and Covid-19 response initiatives, and £29,256 through charitable donations and general fundraising activities as a result of the tireless efforts of our Trustees and supporters.

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.
- £7,451 was spent in connection with Fundraising activities. This included the costs associated with the recruitment of the Fundraising Manager, merchandising items, and event entries.
- £4,800 of unrestricted reserves was spent on the services of a Trusts and Funds Associate.
- Salary costs of £10,983 were incurred.
- £6,741 was spent on the Safe Sleeping research project, as a second interim payment. The responsibility for the balance has been transferred to the Smith-Magenis Syndrome (SMS) Foundation UK CIO.
- £2,948 was spent on the administration needs of the charity.
- £3,154 has been spent on events, including deposits towards the 2021 conference.
- Grants to improve the life of persons with Smith-Magenis syndrome totalled £1,979 and included equipment funding for a tricycle, TV protection, and wheelchairs.
- £48 was used to assist in the production of our publications.

Money assets at the year end of 30 June 2020 was £70,135.01.

### **Reserves Policy**

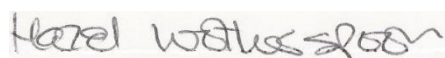
The Foundation has traditionally maintained a prudent financial position of not committing to any expenditure unless the full costs could be covered from reserves. Planned expenditure would be agreed at the start of the financial year based on the value of cash assets held at the end of the previous 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.

With the formation and registration of the Smith-Magenis Syndrome (SMS) Foundation UK CIO, all assets of the existing charity will be transferred to the new charity which will assume full financial responsibilities for any residual incomes and existing commitments. These residual incomes and commitments have extended the transitioning period beyond 30 June 2020.

### **Plans for Future Periods**

During the next financial year, the Foundation intends to continue to deliver activities to meet the objects of the charity, and the transfer of the assets to the Smith-Magenis Syndrome (SMS) Foundation UK CIO to complete the transition to the Charitable Incorporated Organisation. Upon the completion of the transfer of the assets, the Smith-Magenis Syndrome (SMS) Foundation UK (Charity Number 1072573 / SC044841) will be dissolved and deregistered.

Approved by the trustees and signed on their behalf by:



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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**  
**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  
On accounts of the charity for: 01 July 2019 to 30 June 2020  
Charity Registration: Registered UK Charity 1072573  
Registered Scottish Charity SC044841  
Set out on pages: Pages 8 and 9

**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, 1072573 / SC044841**

**Accounts for the year 1<sup>st</sup> July 2019 to 30<sup>th</sup> 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
<b><u>Receipts</u></b>					
<b><u>Voluntary Sources</u></b>					
Donations and membership fees	8	3,093.59	-	<b>3,093.59</b>	16,386.68
Grants	4	-	23,778.00	<b>23,778.00</b>	4,890.00
Receipts from fundraising activities	8	26,162.25	-	<b>26,162.25</b>	27,124.35
Organised Event Income	9	-	-	-	23,999.62
<b>Total Receipts / Income</b>		<b>29,255.84</b>	<b>23,778.00</b>	<b>53,033.84</b>	<b>72,399.65</b>
<b><u>Payments</u></b>					
Expenses for fundraising activities	8	12,251.04	-	<b>12,251.04</b>	3,661.97
Payments relating directly to charitable activities	4,5,7,11	9,737.29	10,983.00	<b>20,720.29</b>	11,202.50
Events	9	3,153.62	-	<b>3,153.62</b>	48,107.76
Grants	10	1,978.94	-	<b>1,978.94</b>	1,261.00
Governance Costs	13	14,075.76	-	<b>14,075.76</b>	8,970.00
Trustee Expenses	6	2,030.48	-	<b>2,030.48</b>	538.76
<b>Total Expenditure / Payments</b>		<b>43,227.13</b>	<b>10,983.00</b>	<b>54,210.13</b>	<b>73,741.99</b>
Total Receipts		29,255.84	23,778.00	<b>53,033.84</b>	72,399.65
Total Payments		43,227.13	10,983.00	<b>54,210.13</b>	73,741.99
<b>Surplus / (Deficit) for the year</b>		<b>(13,971.29)</b>	<b>12,795.00</b>	<b>(1,176.29)</b>	<b>(1,342.34)</b>
Transfers between funds	12	-	-	-	-
<b>Surplus / (Deficit) for the year</b>		<b>(13,971.29)</b>	<b>12,795.00</b>	<b>(1,176.29)</b>	<b>(1,342.34)</b>

The Notes on pages 10 to 12 form an integral part of these accounts.



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

**Statement of Balances on Assets and Liabilities as of 30<sup>th</sup> June 2020**

	£	£	£	£
	Unrestricted	Restricted	Total	Total
<b><u>Fund Reconciliation</u></b>	Funds	Funds	2020	2019
Cash at Bank & In Hand – Start of year	71,311.30	-	<b>71,311.30</b>	72,653.64
Surplus / (Deficit) for the year	(13,971.29)	12,795.00	<b>(1,176.29)</b>	(1,342.34)
<b>Cash at Bank &amp; In Hand – end of year</b>	<b>57,340.01</b>	<b>12,750.00</b>	<b>70,135.01</b>	<b>71,311.30</b>

**Bank & Cash Balances**

<b>The Smith-Magenis Syndrome (SMS) Foundation UK (1072573 / SC044841)</b>	<b><u>30/06/2020</u></b>	<b><u>30/06/2019</u></b>
Barclays Bank Current Account (1072573)	<b>1,841.74</b>	69,355.40
CAF Bank Account (1072573, part of)	<b>64,275.00</b>	-
PayPal Account (1072573)	<b>4,018.27</b>	1,955.90
Cash in Hand	-	-
	<b>70,135.01</b>	71,311.30

**Other Assets (Unrestricted Fund)**

There are no other assets

**Liabilities (Unrestricted Fund)**

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

The Notes on pages 10 to 12 form an integral part of these accounts.

Approved by the Trustees and signed on their behalf by:

*N E 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:

<b>Trust or Fund</b>	<b>Value</b>	<b>Purpose</b>	<b>Period Covered</b>
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

### **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:	£10,983

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

For administrative purposes staff are contracted to Smith-Magenis Syndrome (SMS) Foundation UK CIO, registered charity 1186647.

### **6. Trustee Expenses**

Trustees claimed expenses totalling £2,030.48 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**

As part of the transitioning to the Charitable Incorporated Organisation, £4,800 of unrestricted reserves was spent on the services of a Trusts and Funds Associate.

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

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.

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 £250 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 £1,979 and included:

- £1,000 towards the cost of a specialist wheelchairs,
- £451 towards the cost of a specialist tricycle,
- £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**

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 remaining will be transferred from The Smith-Magenis Syndrome (SMS) Foundation UK (1072573 / SC044841) to The Smith-Magenis Syndrome (SMS) Foundation UK CIO (1186647).

## **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.