

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

ACCOUNTS

30TH JUNE 2019

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

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

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

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THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Annual Report of the Trustees for the year ended 30th June 2019

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 2019.

Reference & Administrative Information

Charity Name:

The Smith-Magenis Syndrome (SMS) Foundation UK

Charity Registration:

UK Registered Charity No 1072573

Registered Scottish Charity SC044841

Address:

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

Current Trustees:

The Charity is administered by a management committee, comprising:

Chairperson:	Hazel Wotherspoon	(Re-elected 30/04/2017)
Trustees:	Nick Hunt	(Re-elected 05/05/2019)
	Nigel Over	(Re-elected 05/05/2018)
	Leeann Stevenson	(Re-elected 05/05/2018)
	Emma Riddell	(Re-elected 30/04/2017)
	Mick Pearson	(Elected 05/05/2018)

Structure Governance & Management

Constitution:

The charity 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. Under the constitution 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 Annual General Meeting held in Solihull on 05 May 2019, Nick Hunt stood down and was re-elected to serve for a further term of three years as 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.

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.

Achievements & Performance:

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

- held member events,
- the charity now has 534 registered supporters and has identified 300 individuals in the UK who have a diagnosis of Smith-Magenis Syndrome,
- attended the PRISMS conference in the USA representing the Foundation,
- actively raised the profile of the Foundation through fundraising and awareness campaigns,
- promote 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,
- delivered the 2019 Conference over four days.

In addition, the Trustees commenced a governance review to formulate a business development strategy for the growth of the charity over the next 1, 3, 5 and 10 years. Having developed and adopted the new vision, mission and values, effort has now moved to enhancing the charity to be able to deliver our strategic objectives effectively and efficiently.

Financial Review

The Trust continued to make extensive efforts to raise funds and support for the charity throughout the year. This year we raised £48,400 through charitable donations and general fundraising activities as a result of the tireless efforts of our Trustees and supporters. This includes payment of the grant funding from Genetic Disorders UK of £4,890 for the partial funding of research into sleep safety in Smith-Magenis syndrome.

Income from events, particularly conference bookings, provided an income of £24,000.

Expenditure of £3,661 was incurred for fundraising activities including entry fees for the Great North Run, the procurement of running vests for our fundraisers, and fundraising awareness banners and merchandise.

£59,849 was spent on charitable activities. £47,750 of which arose from the delivery of the 2019 conference. Initial phase payment for the sleep safety project amounted to £5,900. The costs associated with updating our guidance literature was £5,000. General operating costs were £841.

Grants to improve the life of persons with Smith-Magenis Syndrome totalled £1,261.

The charity has commissioned the services of a consultancy to assist with our governance review, business development strategy and charity restructuring. Of the £22,200 contract value £8,970 has been incurred to date.

Cash reserves at the year end of 30 June 2019 were equivalent to in excess of 10 years running costs, excluding conferences where specific funding is raised to cover the costs of these, with monetary assets of £71,311.

Plans for Future Periods

The Trustees shall continue with the governance review and formulation of a business development strategy for the growth of the charity over the coming years. During the next financial year, the trustees intend to continue to deliver activities to meet the objects of the charity, with specific objectives to:

- promote social gathering and meeting to connect families together,
- 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,
- conclude research into sleep safety and security within Smith-Magenis Syndrome,
- commission research into behaviour improvement utilising vagus nerve stimulation,
- improvement the lives of people with Smith-Magenis Syndrome through the individual small grants scheme,
- 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: 07 October 2019
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 2019

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 the period:	01 July 2018 to 30 June 2019
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: 7/10/19

Name: Mark Middleton

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

FCA

Address: 1 VICARAGE LANE, STRATFORD, LONDON, E15 4HF

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Accounts for the year to 30th June 2019

Statement of Receipts and Payments Account (General Purpose Fund)

Receipts and Payments Account: General Fund

	Note	£ Unrestricted Funds	£ Restricted Funds	£ Total 2019	£ Total 2018
<u>Receipts</u>					
<u>Voluntary Sources</u>					
Donations and membership fees	8	16,386.68	-	16,386.68	3,980.80
Grants	4	-	4,890.00	4,890.00	4,800.00
Receipts from fundraising activities	8	27,124.35	-	27,124.35	15,662.13
Organised Event Income	9	23,999.62	-	23,999.62	372.65
Total Receipts / Income		67,509.62	4,890.00	72,399.65	24,815.58
<u>Payments</u>					
Expenses for fundraising activities	8	3,661.97	-	3,661.97	3,862.98
Payments relating directly to charitable activities	4,5,7,11	6,312.50	4,890.00	11,202.50	3,076.27
Events	9	48,107.76	-	48,107.76	9,397.11
Grants	10	1,261.00	-	1,261.00	483.80
Governance Costs	13	8,970.00	-	8,970.00	-
Trustee Expenses	6	538.76	-	538.76	-
Total Expenditure / Payments		68,851.99	4,890.00	73,741.99	16,820.16
Total Receipts		67,509.62	4,890.00	72,399.65	24,815.58
Total Payments		68,851.99	4,890.00	73,741.99	16,820.16
Surplus / (Deficit) for the year		(1,342.34)	-	(1,342.34)	7,995.42
Transfers between funds	12	-	-	-	-
Surplus / (Deficit) for the year		(1,342.34)	-	(1,342.34)	7,995.42

The Notes on pages 10 & 11 form an integral part of these accounts.

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK

Statement of Balances on Assets and Liabilities as at 30th June 2019

	£ Unrestricted Funds	£ Restricted Funds	£ Total 2019	£ Total 2018
Fund Reconciliation				
Cash at Bank & In Hand – Start of year	72,653.64	-	72,653.64	64,658.22
Surplus / (Deficit) for the year	(1,342.34)	-	(1,342.34)	7,995.42
Cash at Bank & In Hand – end of year	71,311.30	-	71,311.30	72,653.64

Bank & Cash Balances

Barclays Bank Current Account	69,355.40	71,287.27
PayPal Account	1,955.90	1,366.37
Cash in Hand	-	-
	71,311.30	72,653.64

Other Assets (Unrestricted Fund)

There are no other assets

Liabilities (Unrestricted Fund)

	Total Value	2020 Due	2019 Paid
Sleep Safety Research Project (Note 11)	15,590.00	9,690.00	5,900.00
Governance Costs – Strategy Development (Note13)	22,200.00	13,230.00	8,970.00
	37,790.00	22,920.00	14,870.00

All funds are unrestricted.

The Notes on pages 10 & 11 form an integral part of these accounts.

Approved by the trustees and signed on their behalf by:

Nigel Over

Nigel Over (Trustee)

Hazel Wotherspoon

Hazel Wotherspoon (Trustee)

Date: 07 October 2019

Notes to the Accounts – For the Year Ended 30 June 2019

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

One grant was received in the period to 30 June 2019 of £4,890 from Genetic Disorders UK towards partial funding of research into sleep safety in Smith-Magenis syndrome. This grant was fully used within the first phase payment for the research.

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.

6. Trustee Expenses

Three trustees claimed expenses totalling £539 during the period for reimbursement of travelling costs and subsistence relating to activities of the charity.

Reimbursement of expenditure on direct purchases on behalf of the charity is recorded under Administration.

No professional nor legal fees were incurred during 2018-19.

7. Publications

The charity has moved to electronic publishing through the website and social media removing printing of newsletters and other materials.

The technical authoring costs for guidance literature falling due this year was £5,000.

8. Fundraising

Fundraising costs of £400 were incurred in connection with the securing of places in the Great Runs. Awareness clothing for fundraising events cost £410. No charges for places were made. Participants sought individual donations and sponsorship and these are recorded under fundraising income.

General merchandising items cost £2,852.

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

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.

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.

9. Events

Two events were organised during 2018-19.

An event for members in Scotland took place in November 2018 at a cost of £358 with incoming member contributions of £111.

The biennial conference took place over the weekend of 3-6 May 2019. The total cost of the conference was £53,798 with payments made of £47,750 in 2018-19 following deposits of £6,048 paid in 2017-18. Conference related income totalled £23,889.

10. Grants

One £500 grant to improve the life of a person with Smith-Magenis Syndrome was provided towards the cost of an enclosed bed.

A £161 grant to improve the life of a person with Smith-Magenis Syndrome was provided towards the cost of a specialised car seat.

£600 was allocated to providing Kindles for children with Smith-Magenis syndrome who did not have a tablet already. This was from a bequest received where the benefactor expressed a desire that a proportion of the donation should be used directly to improve the lives of children with Smith-Magenis syndrome.

11. Research

A research project on Sleep Safety in Smith-Magenis syndrome has commenced with the University of Birmingham with a total project cost of £15,590. A £4,890 grant towards the costs of this project has been forthcoming from Genetic Disorders UK. An initial payment has been made of £5,900 leaving a balance due of £9,690 in 2019-20.

12. Transfers between funds

No transfers between funds have been necessary during 2018-19.

13. Governance Costs

The trustees have 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 with an initial payment made this year of £8,970. The balance of £13,230 is due in 2019-20.