

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

**ACCOUNTS**

**30<sup>TH</sup> JUNE 2018**

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

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

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

**Contents of the Financial Statements**

**For the year ended 30<sup>th</sup> June 2018**

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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 2018**

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 2018.

#### **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 22/05/2016)
	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 Ashby de la Zouch on 05 May 2018, Nigel Over and Leeann Stevenson stood down and were re-elected to serve for a further term of three years as Trustees. Mick Pearson was elected as a Trustee.

##### **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 throughout the UK to celebrate 25 years of providing support to families affected by a person with Smith-Magenis Syndrome,
- redeveloped our website and social media presence to provide further opportunities for families to connect with one another,
- the charity now has 460 registered members and has identified 285 individuals in the UK who have a diagnosis of Smith-Magenis Syndrome,
- Produced awareness videos explaining life with Smith-Magenis Syndrome,
- developed and host the SMS International Organisations Hub bringing together 17 organisations from across the world in a virtual network for mutual support,
- actively raised the profile of the Foundation through fundraising and awareness campaigns in partnership with Genetic Disorders UK, particularly with "Jeans for Genes Day",
- A representative of the Foundation now attends the annual Genetics Disorders Leadership Symposium to assist in the development of links and collaboration with other organisations with similar focus, aims and objectives.
- completed the rebranding of the charity, registering the logo as a trademark, and emphasising the syndrome through the development of the story behind our logo,
- promote further collaboration in research into Smith-Magenis Syndrome, particularly on the preparation of the sleep safety research project,
- participated in sleep disorder symposiums,
- improved the lives of people with Smith-Magenis Syndrome through the £500 maximum individual small grants scheme, with one grant awarded in 2017-18 well within the 10% of available unallocated funds set limit,
- commenced preparations for the 2019 Conference.

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. As a first stage, the Foundation has developed and adopted new vision, mission and values, identifying core stakeholders and strategic objectives. These are taken forward in projects to deliver our core aims.

## **Financial Review**

The Trust continued to make extensive efforts to raise funds and support for the charity throughout the year. This year we raised £24,816 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 £4,800 for the provision of conference activities for those with Smith-Magenis Syndrome which took place in May 2017.

Expenditure of £3,863 was incurred for fundraising activities comprising entry fees for the Great Runs, the procurement of running vests for our fundraisers, and fundraising awareness banners and merchandise following the introduction of our new branding in May 2017.

£13,630 was spent on charitable activities. £3,349 relate to events celebrating 25 years of the Foundation providing support to UK families and also the costs of the Annual General Meeting. £1,573 awareness video production costs were incurred. Deposits paid with respect to the next conference taking place in May 2019 represented £6,048 of the expenditure. The costs associated with insurance, trademark protection, and general administrative expenditure totalled £1,504.

One grant to improve the life of a person with Smith-Magenis Syndrome was provided for the relocation of an enclosed bed from one family to another at a total cost of £484.

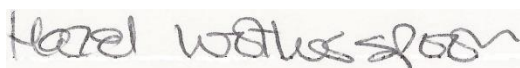
Cash reserves at the year end of 30 June 2018 were equivalent to in excess of 10 years running costs, excluding conferences where specific funding is raised to cover the costs of these, with monetary assets of £72,654.

#### **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:

- organising the UK Conference for May 2019,
- 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,
- commission research into sleep safety and security within Smith-Magenis Syndrome,
- improvement the lives of people with Smith-Magenis Syndrome through the individual small grants scheme,
- enhance member support and fundraising through appropriate database solutions,
- introduce the UK patient registry.

Approved by the trustees and signed on their behalf by:



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Hazel Wotherspoon  
Chairperson

Date: 11 July 2018

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 2018**

**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 2017 to 30 June 2018
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 an independent examination is needed or under Regulation 10(1) (d) of the Charities Accounts (Scotland) Regulations 2006.

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: \_\_\_\_\_

Name: Jai Paragreen

Relevant professional  
qualification(s) or body (if any): CIMA (ACMA CGMA)

Address: 3 Walnut Grove, Leven, Fife, KY8 5PP

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

**Accounts for the year to 30<sup>th</sup> June 2018**

**Statement of Receipts and Payments Account (General Purpose Fund)**

**Receipts and Payments Account: General Fund**

	Note	£ Unrestricted Funds	£ Restricted Funds	£ Total 2018	£ Total 2017
<b>Receipts</b>					
<u>Voluntary Sources</u>					
Donations and membership fees	8	3,574.50	-	<b>3,574.50</b>	16,937.21
Grants	4	-	4,800.00	<b>4,800.00</b>	-
Receipts from fundraising activities	8	15,662.13	-	<b>15,662.13</b>	5,889.67
Organised Event Income	9	139.85	-	<b>139.85</b>	27,931.79
<b>Total Receipts / Income</b>		<b>20,015.58</b>	<b>4,800.00</b>	<b>24,815.58</b>	<b>50,758.67</b>
<b>Payments</b>					
Expenses for fundraising activities	8	3,862.98	-	<b>3,862.98</b>	1,684.99
Payments relating directly to charitable activities	5,7	3,076.27	-	<b>3,076.27</b>	2,979.88
Events	9	9,397.11	-	<b>9,397.11</b>	43,188.30
Grants	10	483.80	-	<b>483.80</b>	1,856.66
Trustee Expenses	6	-	-	-	-
<b>Total Expenditure / Payments</b>		<b>16,820.16</b>	<b>-</b>	<b>16,820.16</b>	<b>49,709.83</b>
Total Receipts		20,015.58	4,800.00	<b>24,815.58</b>	50,758.67
Total Payments		16,820.16	-	<b>16,820.16</b>	49,709.83
<b>Surplus / (Deficit) for the year</b>		<b>4,195.42</b>	<b>4,800.00</b>	<b>7,995.42</b>	<b>1,048.84</b>
Transfers between funds	12	4,800.00	(4,800.00)	-	-
<b>Surplus / (Deficit) for the year</b>		<b>7,995.42</b>	<b>-</b>	<b>7,995.42</b>	<b>1,048.84</b>

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 30<sup>th</sup> June 2018**

	£	£	£	£
	Unrestricted	Restricted	Total	Total
	Funds	Funds	2018	2017
<b><u>Fund Reconciliation</u></b>				
Cash at Bank & In Hand 30/06/2016	64,658.22	-	<b>63,609.38</b>	63,609.38
Surplus / (Deficit) for the year	7,995.42	-	<b>1,048.84</b>	1,048.84
<b>Cash at Bank &amp; In Hand – 30/06/2017</b>	<b>72,653.64</b>	-	<b>64,658.22</b>	<b>64,658.22</b>

**Bank & Cash Balances**

Barclays Bank Current Account			<b>71,287.27</b>	61,887.15
PayPal Account			<b>1,366.37</b>	2,771.07
Cash in Hand			-	-
			<b>72,653.64</b>	<b>64,658.22</b>

**Other Assets (Unrestricted Fund)**

There are no other assets

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**Liabilities (Unrestricted Fund)**

There are no liabilities outstanding

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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: 11 July 2018

## **Notes to the Accounts – For the Year Ended 30 June 2018**

### **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 2018 of £4,800 from Genetic Disorders UK towards 2017 conference costs already incurred.

### **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.

Securing trademark protection of the charity's logo with the Intellectual Property Office incurred fees of £420. The trademark is awarded for an initial period of ten years.

### **6. Trustee Expenses**

No trustees claimed expenses during the period outside of reimbursement of direct purchases and travelling costs on behalf of the charity and recorded under Administration.

No professional nor legal fees were incurred during 2017-18.

### **7. Publications**

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

£1,573 of expenditure related to the production of awareness videos.

### **8. Fundraising**

Fundraising costs of £875 were incurred in connection with the securing of places in the Great Runs. Awareness clothing for fundraising events cost £753. No charges for places were made. Participants sought individual donations and sponsorship and these are recorded under fundraising income.

Promotional banners cost £363.

General merchandising items cost £1,872.

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**

A number of events were held around 17 November 2017 to mark the 25<sup>th</sup> anniversary of the Foundation providing support to UK families. The Annual General Meeting took place in May 2018 in Ashby de la Zouch. The cost of these events was £3,311. Contributions towards these events totalled £140.

£39 was paid out as speaker expenses due from the 2017 conference.

Deposits paid with respect to the next conference taking place in May 2019 represented £6,048 of the expenditure.

#### **10. Grants**

One grant to improve the life of a person with Smith-Magenis Syndrome was provided for the relocation of an enclosed bed from one family to another at a total cost of £484.

#### **11. Research**

No further research expenditure was incurred during 2018-19.

#### **12. Transfers between funds**

During the year, the charity received a grant from Genetics Disorders UK of £4,800 in agreement for the funding of the activities at the conference in May 2017. As this had been paid in advance in the year to 30/06/2017 from unrestricted funds, the grant was transferred from restricted funds to unrestricted funds upon receipt in December 2017.