

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

Registered UK Charity No: 1186647

Registered Scottish Charity (SCIO) No: SC050921

**ACCOUNTS**

**30<sup>TH</sup> JUNE 2023**

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**Registered Address:**

Smith-Magenis Syndrome (SMS) Foundation UK  
18 Suthmere Drive  
Burbage  
Marlborough  
SN8 3TG

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**Operating and Registered Address in Scotland:**

Smith-Magenis Syndrome (SMS) Foundation UK  
28 Kilbrennan Drive  
Tamfourhill  
Falkirk  
FK1 4SG

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

**Contents of the Financial Statements**

**For the year ended 30<sup>th</sup> June 2023**

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

### Annual Report of the Trustees for the year ended 30<sup>th</sup> June 2023

The Trustees have pleasure in presenting their report together with the financial statements and the independent examiner's report for the year ended 30<sup>th</sup> June 2023.

#### Reference & Administrative Information

Charity Name	Charity Registrations
The Smith-Magenis Syndrome (SMS) Foundation UK CIO	UK Registered Charity No 1186647 Registered Scottish Charity SC050921

#### Registered Address

The Smith-Magenis Syndrome (SMS) Foundation UK,  
18 Suthmere Drive, Burbage, Marlborough, SN8 3TG

#### Operating and Registered Address in Scotland

The Smith-Magenis Syndrome (SMS) Foundation UK,  
28 Kilbrennan Drive, Tamfourhill, Falkirk, FK1 4SG

#### Trustees

Name	Elected	Re-Elected	Resigned
Hazel Wotherspoon (Chairperson)	16/11/2019	25/01/2022	
Nick Hunt	16/11/2019		03/10/2022
Emma Riddell	16/11/2019	25/01/2022	
Mick Pearson	16/11/2019	25/01/2022	
Laura Maddocks	12/01/2021		
Wendy Ferguson	12/01/2021		
Rosina Mosedale	25/01/2022		13/01/2023
Jayne Dainty	25/01/2022		

Jacqueline Jenkins and Debbie Brooks are co-opted non-trustee members of the Board.

#### Structure, Governance & Management

##### Constitution

**The Smith-Magenis Syndrome (SMS) Foundation UK CIO**, 1186647, is a Charitable Incorporated Organisation (CIO). It is governed by its Foundation constitution which was adopted on 16<sup>th</sup> November 2019. The Smith-Magenis Syndrome (SMS) Foundation UK CIO became registered with the Charities Commission on 28<sup>th</sup> November 2019, and with OSCR as a Scottish Charitable Incorporated Organisation (SCIO) SC050921 on 21<sup>st</sup> April 2021.

##### 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 states that there must be no fewer 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.

A small part-time team is employed to run day-to-day operations. At the date of signing this report, this team comprises:

- Communications Manager & Programmes Lead: Leeann Stevenson
- Fundraising Manager: Helen Hargrave
- Research & Sector Engagement Manager: Natasha Craven

## **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.

### Background

The SMS Foundation UK ("The Foundation") was set up as a parent support group in 1992 and until 2019 operated as an entirely volunteer-led, small, registered charity. The Trustees agreed that more resources and income would be required to meet the increasing demands and needs of the SMS community. It was decided to change the charity status to a CIO (Charitable Incorporated Organisation) to minimise personal risk, maximise financial potential and introduce staff to support and grow service delivery. In 2019, the Foundation UK began the transition to dissolve the UK and Scottish unincorporated charities and register as a CIO in England and SCIO in Scotland and completed this in April 2021.

### Achievements & Performance

We have responded to 153 enquiries from parents and caregivers seeking advice and emotional support, this reflects an increase of 82% compared to the previous year. Our three dedicated volunteers are spending an average of 60 hours collectively per month to respond to incoming enquiries. We firmly believe that access to reliable information and emotional support is crucial for these families.

Our membership and subscriber list has increased by 10% in the past year. We continue to see steady growth in website traffic and across social media platforms. Our Facebook community has grown to 2.7k followers, with a 120% increase in reach over the past 12 months. These figures signify the increasing recognition and trust that our organisation has garnered within the SMS community and beyond.

We have successfully delivered awareness and training presentations to two schools, helping educators better understand and accommodate the unique needs of students with SMS. Additionally, we have helped three families with funding towards equipment and funeral costs through our family small grants scheme.

One of our major achievements was the successful completion of a comprehensive community survey, which garnered responses from over 100 individuals and families living with SMS. This invaluable feedback has allowed us to gain deeper insights into the challenges and needs faced by our community. As a direct result of this input, we have developed a comprehensive 5-year strategy that incorporates the support and services that our community has expressed a pressing need for.

In addition to refining our strategic direction, we have also conducted a complete rebranding of the SMS Foundation. This initiative involved a fresh new logo, an updated strapline, and a careful re-evaluation of our vision, mission, and values. This rebranding effort reaffirms our commitment to adapt and evolve in line with the evolving needs of the SMS community.

Our dedication to operational excellence extended to our Customer Relationship Management (CRM) system, which we continued to develop and optimise. We have also redesigned and developed our website which is almost ready to launch along with our new brand assets.

In collaboration with esteemed institutions like Keele University, Aston University, and The University of St Andrews (ScotGEM) we have hosted nine interns. Their research has spanned subjects such as physical health, behaviour, diet and obesity, education, transition to adult services, commercial strategy, a training strategy, adult residential options, and medical awareness and guidelines. These partnerships have enriched our knowledge base and enhanced our ability to advocate effectively for the SMS community.

We continue to nurture and strengthen our partnerships with other patient advisory groups and networks. These partnerships enable us to pool resources, share best practices, and advocate collectively for the needs of individuals and families affected by rare diseases, fostering a broader and more inclusive community of support. At the end of 2022 we were invited to share our knowledge and experience with another rare disease charity by delivering an in-person presentation on our vision. This collaboration reflects our commitment to knowledge-sharing and expanding our impact beyond the SMS community.

## **Financial Review**

Extensive efforts were made to raise funds and support for the Foundation throughout the year. Income of £82,983 was received this year. £16,955 came from grants and £66,028 came through charitable donations, legacy, and general fundraising activities.

Expenditure for the year totalled £89,727. This was spent as follows:

- £76,712 on total staff costs.
- £2,996 on administration, insurance, software licences and membership subscriptions.
- £1,201 on staff and trustee training and development.
- £1,621 on research projects.
- £5,432 for fundraising activities. This included enhanced fundraising platform subscriptions, promotional materials, merchandising items, and event entries.
- £290 on awareness merchandise and postage and packing costs.
- £70 on banking costs.
- £1,205 in small grants to SMS families towards the cost of essential equipment.
- £200 small social grant to bring families together through our REPs programme.

Cash balances at the year-end amounted to £36,964, of which £17,241 is restricted funding. Further detail on income and expenditure and the purpose of the restricted funding held at the year-end is shown on pages 15 to 17.

## **Reserves Policy**

The intention of the Foundation is to seek to retain a minimum of 12 months of core operating expenditure as the basis of its cash reserves, excluding restricted funding for projects.

At the year end, the Foundation held unrestricted cash reserves covering 4 months of core operating costs. If the costs of employees who will be directly working on already funded projects in the year ahead are excluded, then cash balances covering 6 months of core operating costs were held at the year end.

The Foundation is working to increase its cash reserves to the 12-month targeted level.

## **Plans for Future Periods**

Earlier this year, The SMS Foundation conducted a comprehensive community survey to better understand the challenges faced by families living with SMS. The survey revealed alarming statistics that underscore the pressing need for support. Some of the feedback we received, included:

- 83% have sought emotional support from The SMS Foundation.
- 70% of SMS families experience regular isolation or loneliness.
- 69% have found accessing education for their child with SMS moderately or severely challenging.
- 46% have had to give up their jobs to care for a person with SMS.
- 46% have faced negative financial impacts due to SMS.
- 29% have been unsuccessful in obtaining respite support from their local authorities.

In response to these findings, The SMS Foundation has developed a five-year strategy aimed at addressing these challenges. Our purpose is to improve the quality of life of everyone living with SMS through awareness, understanding, and a supportive community. We aim to achieve this by ensuring that every person with SMS is surrounded by caregivers and professionals who are well-equipped and empowered to meet their unique needs.

Over the next five years, The SMS Foundation is committed to pursuing the following key initiatives:

1. Prioritising community needs
2. Knowledge enhancement
3. Building collaborative networks
4. Strengthening our team
5. Growing our supporter base
6. Ensuring sustainability
7. Enhancing engagement

We have developed four core programmes, designed to address the challenges faced by the SMS community and provide essential support. These programmes are aligned with our key initiatives, and our aim is that they will have the following impact:

- Increased levels of confidence and number of families and carers empowered and equipped to support a person with SMS.
- Reduced number of families feeling isolated and alone.
- Increased knowledge, awareness, and understanding within the community, and in wider society.
- Improved access to vital emotional, practical, and financial support.
- Reduced levels of crisis and distress within the community.
- Enhanced levels of support that meets the needs of people with SMS.
- Positive educational outcomes and opportunities in adulthood.

## **Programme 1 - Carer Support Service**

Projects and outputs in this programme include:

### **1. Community Wellbeing Service**

Our triage service aims to implement processes to improve our response rates to incoming enquiries, and enhance emotional and practical support to families dealing with a new SMS diagnosis. We will develop safety measures and crisis intervention processes while collaborating with partners to support counselling. We will provide training for our dedicated volunteers to strengthen the assistance we offer.

### **2. Online Resources**

We will actively promote carer well-being by publishing various online articles, resources, and advice. Additionally, we're improving our online signposting to make it easier for caregivers to access practical support, while also sharing inspiring stories from SMS families to offer hope and valuable guidance to our community.

### **3. Advocacy, Referrals, and Small Grants**

We will streamline support by creating an application process and managed service for advocacy, referrals, and small grants. This involves partnering with advocacy providers, establishing service level agreements (SLAs), and collaborating with equipment providers. We'll also highlight the positive impact of these services by sharing success stories from individuals who have benefited.

### **4. SMS Passport**

Our aim is to create an SMS passport prototype to communicate personalised needs and care plans, followed by a pilot scheme with recruited volunteers to assess its effectiveness. We'll showcase success stories from individuals who have benefited from the SMS Passport to demonstrate the positive impact we anticipate for caregivers, individuals with SMS, and the broader community.

## **Programme 2 - Education Support Service**

Projects and outputs in this programme include:

### **1. Online Education Resources**

We are developing resources such as parent guideline documents to support parents through the EHCP (or alternative) process. Additionally, we will also provide education recommendations for SEND lead workers and teaching staff in schools.

## **2. 1:1 Education Referral service**

This referral service aims to provide tailored ‘person-centred’ support to families who are struggling to access an adequate education plan (EHCP) and support within their educational setting. We will collaborate with partners who can help us deliver support and advocate the complex needs of students with SMS.

## **3. SEND Policy Campaign**

This long-term initiative will focus on advocating and campaigning for positive changes to education policy. Key objectives will include submitting a Greenpaper on Special Educational Needs and Disabilities (SEND) to influence policy and collaborating with rare disease organisations to amplify our impact.

## **Programme 3 – Training Programme**

Projects and outputs in this programme include:

### **1. Online Training Resources**

We provide a range of accessible online training resources, including guides, practical references, and instructional videos to equip parents and carers with valuable knowledge and skills.

### **2. 1:1 Educational Training Courses**

Our in-person training course is designed specifically for teachers in a school setting, accompanied by printed course materials for reference. We will also offer ongoing support outreach to ensure teachers have the assistance they need.

### **3. Parents and Caregiver Workshops**

Other learning options for parents and carers will include group workshop events for immersive learning experiences. Members also have access to workshop videos, printed materials for reference, and valuable insights from real-life case studies and user success stories to enhance their knowledge and skills.

### **4. Medical Professionals Awareness and Guidance**

We will increase awareness to medical professionals through a combination of online and print campaigns. We will also provide guidance information and access to videos ensuring healthcare professionals have the resources they need for enhanced patient care.

## **Programme 4 – Awareness and Advocacy Programme**

Projects and outputs in this programme include:

### **1. Community Activities and Events**

We aim to provide a variety of engaging activities and events to bring the SMS community together. This encompasses a biennial National SMS community event, online thematic community activities for broader participation, and in-person regional community events to foster local connections and support.



## **2. Awareness and Policy Campaigns**

We will conduct generic awareness and thematic 'symptom' campaigns to educate the public about SMS. Additionally, we engage in policy campaigning to advocate for legislative changes, to ensure better support and opportunities for individuals with SMS.

## **3. Networks and Research**

We aim to strengthen and expand our relationships with other SMS organisations, and Rare Disease Networks to enhance collaboration and support. Additionally, we're working to establish a solid relationship with our Scientific and Clinical Advisory board to benefit from their expertise. We will continue to facilitate research initiatives by hosting 1-2 students per year to conduct research projects.

## **4. Medical Clinics**

To enhance our support for the SMS community, we would like to pilot an SMS consultation clinic at national events. Our medical clinics will provide a platform for parents to connect with professionals knowledgeable about SMS, fostering valuable interactions and information exchange.

## **Note of Recognition and Appreciation**

It is with gratitude that we acknowledge the contributions made by Nigel Over during his time as both a trustee and CEO of The SMS Foundation UK.

Nigel's journey with The SMS Foundation began in 2012 when he joined as a trustee with a visionary commitment to the mission of the organisation. His dedicated efforts led to the restructuring of the Foundation's governance framework, resulting in the implementation of a new constitution, enhanced accounting practices, and a revitalised branding strategy. Additionally, as a trustee Nigel played a pivotal role in supporting new charitable activities and awareness campaigns.

As a trustee, Nigel helped to organise a series of SMS conferences in 2013, 2015, 2017, and 2019. These conferences served as vital platforms for caregivers and professionals to convene, share knowledge, and foster a sense of community. Keen to progress understanding in the field and research into SMS, he supported several studies on sleep and behaviour.

Nigel was responsible for strengthening our SMS Professional Advisory Board during this time, providing invaluable guidance to parents, teachers, and medical professionals. Furthermore, he established the SMS Global Hub Facebook Group, an initiative that united multiple patient groups facing similar challenges worldwide.

During 2020 he managed the transition of The SMS Foundation from a registered charity to a Charitable Incorporated Organisation (CIO) of which he later became CEO.

As CEO, Nigel has shown personal dedication and commitment to families living with SMS. He was instrumental in coordinating the Regional Parent Supporters scheme; volunteers situated in different geographical regions who provide crucial local support to families. He provided significant contribution and co-authoring to the study titled 'Caregivers' Experience of Sleep Management in SMS,' which was published in the prestigious Orphanet Journal of Rare Diseases.

In 2022 the SMS Foundation delivered its biennial conference which held special significance as it marked the celebration of the Foundation's 30th anniversary. During this event Nigel facilitated a workshop with several Patient Engagement and Advisory Groups. This collaboration served as a

platform to deliberate on the implementation strategies of the UK Rare Disease Framework, underlining his commitment to advocating for the broader rare disease community.

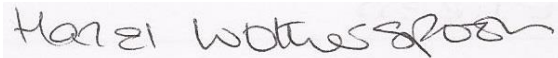
In his role as CEO, Nigel has delivered training sessions to a variety of sectors including classrooms where he has championed person-centred support for SMS children. He has engaged with NHS learning disability teams, care organisations, and adult day service providers delivering SMS awareness and training. His approach has not only showcased his dedication to promoting inclusivity and understanding but also left a lasting impression on all those he interacted with.

Additionally, Nigel's networking skills have played an integral role in forging robust partnerships that will undoubtedly benefit The SMS Foundation in the future. He has established an internship programme, supporting opportunities that have paved the way for research into SMS. Through these initiatives, previously understudied areas such as demographics, vision impairment, education, adult living options, and SMS health have yielded invaluable insights.

Financial pressures at the start of 2023, arising from external factors impacting grant giving and donations, led to the Board deciding on the need to reduce ongoing core costs whilst sustainable income streams are found. With many elements of the strategic development led by Nigel complete and ready to implement, the role of CEO was regrettably made redundant. Since then, people management, administrative duties, and delivery of programmes are now being covered by trustees, staff, and volunteers. The SMS Foundation are now dedicating time to launching the new five-year strategy, ensuring its mission to support families living with SMS continues.

The SMS Foundation would like to thank Nigel for the legacy he leaves behind and extend our heartfelt best wishes as he embarks on new horizons, confident that his impact will continue to shine.

Approved by the trustees and signed on their behalf by:



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Hazel Wotherspoon – Chairperson

Date: 18<sup>th</sup> October 2023

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

**Independent Examiner's Report to the Trustees of**  
**THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO**  
**For the year ended 30<sup>th</sup> June 2023**

**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: 1<sup>st</sup> July 2022 to 30<sup>th</sup> June 2023  
Charity Registration: Registered UK Charity 1186647  
Scottish Registered Charity (SCIO) SC050921  
Set out on pages: Pages 13 to 17

**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: 18<sup>th</sup> October 2023

Name: Julie Russell

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

Address: 34 Orchard Drive, Edinburgh, EH4 2DZ

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

**Accounts for the period 1<sup>st</sup> July 2022 to 30<sup>th</sup> June 2023**

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

**Receipts and Payments Account: General Fund**

		£	£	£	£
		Unrestricted	Restricted	Total	Total
<b><u>Receipts</u></b>	Note	Funds	Funds	2023	2022
<b><u>Voluntary Sources</u></b>					
Donations and membership fees	8	35,940	750	<b>36,690</b>	24,203
Legacies	8	9,523	-	<b>9,523</b>	989
Grants	4	1,000	15,955	<b>16,955</b>	35,228
Receipts from fundraising activities	8	18,925	-	<b>18,925</b>	19,859
Gross receipts from trading		785	-	<b>785</b>	2,062
Income from investments		67	-	<b>67</b>	4
Organised Event Income	9	38	-	<b>38</b>	23,345
<b>Total Receipts / Income</b>		<b>66,278</b>	<b>16,705</b>	<b>82,983</b>	<b>105,691</b>
<b><u>Payments</u></b>					
Expenses for fundraising activities	8	5,432	-	<b>5,432</b>	3,210
Gross Trading Payments	8	290	-	<b>290</b>	3,918
Banking / Investment costs		70	-	<b>70</b>	96
Payments relating directly to charitable activities:					
Staff Costs	5	69,647	7,065	<b>76,712</b>	77,699
Training & Development Costs	5	1,201	-	<b>1,201</b>	-
Research Costs	5	-	1,621	<b>1,621</b>	-
Administration & Office Costs	5	591	-	<b>591</b>	1,697
Software Licences	5	2,248	-	<b>2,248</b>	2,366
Insurance	5	157	-	<b>157</b>	253
Equipment		-	-	-	48
Subscriptions & Entrance Fees		-	-	-	383
Publications	7	-	-	-	201
Events	9	200	-	<b>200</b>	44,738
Grants	10	205	1,000	<b>1,205</b>	500
Governance Costs	13	-	-	-	-
Trustee Expenses	6	-	-	-	-
<b>Total Expenditure / Payments</b>		<b>80,041</b>	<b>9,686</b>	<b>89,727</b>	<b>135,109</b>
Total Receipts		66,278	16,705	<b>82,983</b>	105,691
Total Payments		80,041	9,686	<b>89,727</b>	135,109
<b>Surplus / (Deficit) for the year</b>		<b>(13,763)</b>	<b>7,019</b>	<b>(6,744)</b>	<b>(29,418)</b>
Transfers between funds	12	-	-	-	-
<b>Surplus / (Deficit) for the year</b>		<b>(13,763)</b>	<b>7,019</b>	<b>(6,744)</b>	<b>(29,418)</b>

The Notes on pages 15 to 17 form an integral part of these accounts.

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

**Statement of Balances on Assets and Liabilities at 30<sup>th</sup> June 2023**

	£	£	£	£
	Unrestricted	Restricted	Total	Total
	Funds	Funds	2023	2022
<b><u>Fund Reconciliation</u></b>				
Cash at Bank & In Hand – Start of year	33,486	10,222	<b>43,708</b>	73,126
Surplus / (Deficit) for the year	(13,763)	7,019	<b>(6,744)</b>	(29,418)
Transfer of Assets from 1072573	-	-	-	-
<b>Cash at Bank &amp; In Hand – end of year</b>	<b>19,723</b>	<b>17,241</b>	<b>36,964</b>	<b>43,708</b>

**Bank & Cash Balances**

CAF Bank Account	<b>32,671</b>	41,600
PayPal Account	<b>4,293</b>	2,108
Cash in Hand	-	-
	<b>36,964</b>	<b>43,708</b>

**Other Assets (Unrestricted Fund)**

There are no other assets

- -

**Liabilities (Unrestricted Fund)**

No current unrestricted fund liabilities

- -

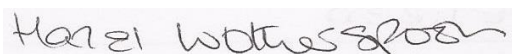
**Liabilities (Restricted Fund)**

No current restricted fund liabilities

- -

The Notes on pages 15 to 17 form an integral part of these accounts.

Approved by the Trustees and signed on their behalf by:



Hazel Wotherspoon (Chairperson)

Date: 18<sup>th</sup> October 2023

## Notes to the Accounts – For the Year Ended 30<sup>th</sup> June 2023

### 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 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 some restricted funding in the form of grants and donations.

### 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 and Donations

The following grants were received in prior years and spent in 2022-2023: (Total £9,686)

Grant	Provider	Purpose	Used for
£3,686	Charities Trust (Nationwide Building Society)	Core Costs	Adult residential internship project
£1,000	New Forest Business Club	Core Costs	Family small grants scheme
£5,000	Foyle Foundation	Core Costs	Information and Support Service: Internship supervision for information research projects and web-based guidance

The following grants and donations were received in 2022-2023: (Total £17,705, of which £1,000 was spent in the year)

Amount	Provider	Purpose	Used for
£750	Anonymous donation	Help with costs of attending a conference event	There was no family conference in 2022/23 so this is carried forward
£1,000	Marks & Spencer/ The Neighbourly Foundation	Family support	Salaries associated with delivery of support
£5,000	Mercers Company	Expansion and development of the Volunteer Engagement Strategy	This work will take place in 2023/24
£2,000	Meikle Foundation	Two in-person family events	These will take place in 2023/24
£8,955	The National Lottery Community Fund	The Scottish Volunteer Engagement Plan and a programme of awareness training modules for Scotland	This work will take place in 2023/24

The following restricted grants and donation balances are being held for use in future years:  
(Total £17,241)

Grant	Provider	Purpose
£536	Private Donation	To help families attend the conference
£8,955	The National Lottery Community Fund	The Scottish Volunteer Engagement Plan and a programme of awareness training modules for Scotland
£5,000	Mercers Company	Expansion and development of the Volunteer Engagement Strategy
£2,000	Meikle Foundation	Two in-person family events
£750	Private Donation	To help families attend the conference

## 5. Administration Costs

These are the costs of running the charity and are as follows:

- Insurance premiums £157.
- Software licences £2,248. These relate to a membership database and an electronic mailing application.
- Staff training and development £1,201.
- Payroll bureau and stationery and postage £591.

### Staff Costs

Average number of staff employed: 4 (1.8 FTE)  
 Period of employment: 1<sup>st</sup> July 2022 to 30<sup>th</sup> June 2023  
 Staff salaries including taxes and pensions: £76,712\*  
 No member of staff has a salary above £60,000 p.a.

\* This includes £5,972 in respect of statutory redundancy pay, pay in lieu of notice and accrued holiday pay, as a result of the role of Chief Executive Officer being made redundant to reduce permanent staff costs.

## 6. Trustee Expenses

No Trustees claimed expenses during the reporting period.

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 or legal fees were incurred during the year.

## 7. Publications

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

## 8. Fundraising

Donations are recorded based on receiving an altruistic gift, either with a general charitable purpose, or for the support of a project. 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.



The Foundation received donations totalling £35,940 from various individuals and organisations with the highest single donation being for £10,000. In addition, a donation of £750 was received for the specific purpose of assisting families with the costs of attending an SMS conference.

Income raised by the SMS community totalled £18,925. Expenses for fundraising activities relate to expenditure on sports event entry fees, fundraising merchandise and donation platform fees and subscriptions and totalled £5,432.

In memorial donations (also known as legacies) were £9,523.

Gross receipts from trading comprise sales of awareness merchandise through the charity's online shop of £135, and £650 from the delivery of SMS awareness sessions. Expenditure relating to trading totalled £290 and comprised the cost of merchandise and postage and packing.

#### **9. Events**

A regional event took place during the year in Lancashire, organised by one of the local volunteers. The charity contributed £200 towards its cost.

#### **10. Grants**

Three grants to improve the life of a person with Smith-Magenis syndrome and their families were awarded totalling £1,205. These were £500 towards funeral costs, £500 towards the cost of an induction hob, and £205 towards the cost of a scooter.

#### **11. Research**

Research into Adult Residential Options was undertaken at a cost of £3,686. Specific costs, in addition to the Foundation staff's time, were £1,621.

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

No transfers are recorded as taking place between funds during the year.

#### **13. Governance Costs**

No governance costs were incurred during the year.