

# FINANCIAL REVIEW

## 2022-23



**Spinal  
Muscular  
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING



# ABOUT SMA UK

Founded in 1985, Spinal Muscular Atrophy UK is the UK's leading charity for Spinal Muscular Atrophy (SMA), a rare, genetic, neuromuscular condition that causes muscle weakness and loss of movement.

## **Our Vision**

Everyone affected by SMA will have access to the best care, support and treatment and there will be no barriers preventing full inclusion in society

## **Our Mission**

We work tirelessly to raise awareness of SMA, to be a leading advocate for individuals and families and to ensure timely access to diagnosis, effective treatment and best management for all affected by SMA.

We listen to and support our community to make informed choices and will bring together skills, knowledge and resources in the UK and beyond, in our quest to optimise the future lives of all affected by SMA.

## **Our Guiding Principles**

Spinal Muscular Atrophy (SMA) is a complex and rare neuromuscular condition that affects each individual and their family differently. We will always be respectful of each person's needs and choices. All face the challenge of obtaining the right support, care and opportunities to enable them to live long and fulfilling lives; some face the distress of early bereavement.

A photograph of a man in a white shirt and tie, wearing a lanyard, leaning over a table to talk to a young boy in a wheelchair. The boy is also wearing a lanyard. They are in an office setting with a window and blinds in the background. The image is overlaid with a teal color filter.

# TREASURERS REPORT

Income for the year was £924k an increase of nearly 9% on the prior year. The charity benefited from a National Lotteries Grant of £154k and community fundraising has been an important source of income again this year with tremendous efforts from the fundraising team and trustees.

The total pharmaceutical funding received during the year was £314k made up of £208k for support services and £107k for Newborn Screening Alliance together this was 34% of total income as compared to 5% in the prior year. Specific donations received in 2022/23 were £150k from Novartis, £41k from Roche, £9k Abbvie and £8k Scholar Rock. In addition, the following Pharma companies supported the Newborn Screening Alliance: Novartis £67k and Roche £40k. We are committed to transparency on pharmaceutical funding and ensure that we do not accept funding from any party if we feel it will place the charity under undue pressure to act in a way that does not support or compromises our charitable objectives or independence.

SMA UK's spending is broadly divided between information provision, support and research – our charitable purpose – and fundraising and administration. We aim to maximise spending on our core purpose and ensure that other costs are carefully monitored. This year, the charity has had to cope with inflationary increases in its staff costs.

The fundraising team is now at full strength led by a Head of Communications and Fundraising to engage in both fundraising and communications work.

Overall there has been an increase in expenditure in the year of £142k or 16.5%. I am pleased to report that the proportion of our costs that was spent on our charitable purpose, our value in the pound, rose from 68p to 69p as resources were focused on provision of support to the SMA community, the Newborn screening Alliance and research.

Our net income for 2022/23 was a surplus of £67k compared to £124k in the prior year. Value for money in our activities and the control of expenditure remains a priority so that the charity is sustainable for the future. As we look to 2023/4 there is continued pressure on fundraising and the need for trust, major donor and pharmaceutical support, especially given the general economic and inflationary environment. We have finished the year with a strong cash position of £628k and the board will continue to monitor activities and reserves very carefully.



A handwritten signature in black ink, appearing to read 'K Jackson'.

**Katherine Jackson**  
Treasurer

\*Figures have been taken to the nearest decimal place for the numbers against the pharma income



# FINANCIAL REVIEW

# REPORT OF THE TRUSTEES

## for the Year Ended 31 March 2023

The trustees who, until 4th August 2022, when SMA UK became a Charitable Incorporated Organisation (CIO), were also directors of the organisation for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

## OBJECTIVES AND ACTIVITIES

### Objectives and aims

As stated in its Constitution, Spinal Muscular Atrophy UK is established for:

- 3.1 The relief of people living with Spinal Muscular Atrophy and related medical conditions and to raise the public's awareness of such conditions.
- 3.2 The relief of persons who are in need after experiencing a bereavement or loss due to Spinal Muscular Atrophy.
- 3.3 The promotion of research into the causes and treatment of Spinal Muscular Atrophy.

### Public benefit

The Trustees confirm that they have referred to the guidance contained in the Charity Commission's General Guidance on Public Benefit when reviewing the Charity's aims and objectives and in planning future activities.

## STRATEGIC REPORT

### Achievement and performance

A detailed overview of the charity achievements and performance can be found in the Annual report 2023.

### Future plans

We will continue to listen, advocate and take action on the needs of the SMA community and continue to raise awareness of SMA. The charity will be critical to ensure that we get continued universal access to treatment for every person of all ages and abilities in the SMA community.

We are already strongly advocating through the UK NBS Alliance and parliamentarians to ensure the UK Newborn Screening Committee include SMA into the existing heel pick test. We are acutely aware that further delays can have a devastating impact for families recently diagnosed with the condition and the need for speed is imperative.

The SMAUK team will be working with adults living with SMA to ensure their voices are fundamental in any decision making when shaping the SMA Care UK project.

We know that there are several clinical trials in the pipeline for complementary therapies and our team will make sure the SMA community has up to date, industry recognised information and can make informed decisions to whether they would like to be involved in any trials.

As a charity we would not be able to carry out our vital work were it not for our incredible supporters and donors. We will develop a clear strategic plan to ensure the long-term sustainability of the charity that focuses on the SMA community needs and priorities and drives life enhancing change.

## **FINANCIAL REVIEW**

### **Katharine Jackson**

Treasurer

#### **Investment policy**

No investments are currently held by the Charity. The investment policy is reviewed annually.

#### **Reserves policy**

**Restricted reserves** will always be applied in accordance with the Trust/donor's award specification. Where there is no specific budget, an element or general (core) overheads will be recovered against those reserves. The percentage recovery date is a matter of judgement; however, costs allocated will be reasonable, proportionate, justifiable and transparent.

**Unrestricted cash reserves** should be not less than three months of unrestricted expenditure, based on the most recent three-months of unrestricted expenditure.

In response to the cost of living crisis and high inflationary environment, Trustees have reduced the reserves policy to two months of predicted future expenditure with an additional buffer of £100,000 to be held in reserve in case of unforeseen funding issues.

# STRUCTURE, GOVERNANCE AND MANAGEMENT

## GOVERNING DOCUMENT

The Charity is governed by its Constitution .

## APPOINTMENT OF TRUSTEES

Trustees are recruited as required to fill specific gaps and to complement the management experience of the Board of Trustees. Appointments are made in accordance with the Constitution, after the appointment has been approved by the resolution of Trustees.

## ORGANISATIONAL STRUCTURE

All policy, strategy and financial decisions relating to the Charity have to be formally approved by the Board of Trustees. The Board meets four times a year with an additional meeting for the AGM. Meetings are held virtually or at the charity's offices in Stratford upon Avon or suitable venue.,

## RISK MANAGEMENT

The Trustees have a duty to identify and review the risks to which the Charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The Trustees carried out regular reviews of the key risks affecting the Charity in the course of the year and took appropriate action. This is recorded on a Risk register

# REFERENCE & ADMINISTRATIVE DETAILS

## Registered Company number (until 4th August 2022)

05137534 (England and Wales)

## Registered Charity number

1106815

## Company Secretary

A Smith-Morgan

## Trustees

T J D Sheffield C S B Knight D J Waltier

Dr R Quinlivan T J Mildon

M T Dearlove K M Jackson M P Collins

B M O Morris L E J West Dr A M E Smith

Dr A M Childs

K Y Edwards J M Fiorentini

S Madipalli C M Gray

## Registered office

Unit 9 Shottery Brook Office Park

Timothy's Bridge Road

Stratford upon Avon Warwickshire

CV37 9NR

## Auditors

Cooper Adams Ltd Chartered

Accountants and Statutory Auditors 12

Payton Street Stratford upon Avon

Warwickshire

CV37 6UA

## Patrons

Professor V Dubowitz



# TRUSTEES' RESPONSIBILITY STATEMENT

The trustees (who were, until 4th August 2022, also the directors of Spinal Muscular Atrophy UK for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charitable Incorporated Organisation and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charity SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the Charitable Incorporated Organisation and to enable them to ensure that the financial statements, until 4th August 2022, complied with the Companies Act 2006. They are also responsible for safeguarding the assets of the Charitable Incorporated Organisation and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the Charitable Incorporated Organisation auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company trustees, on 16/08/2023 and signed on the board's behalf by:



.....  
M T Dearlove - Trustee

## **OPINION**

We have audited the financial statements of Spinal Muscular Atrophy UK (Charitable Incorporated Organisation) for the year ended 31 March 2023 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- Give a true and fair view of the state of the Charitable Incorporated Organisation affairs as at 31 March 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland';
- Have been prepared in accordance with the requirements of the Charities Act 2011;

## **BASIS FOR OPINION**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charitable Incorporated Organisation in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## **CONCLUSIONS RELATING TO GOING CONCERN**

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charitable Incorporated Organisation ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

## **OTHER INFORMATION**

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

## **Matters on which we are required to report by exception**

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- The information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- The Charitable Incorporated Organisation has not kept adequate accounting records; or
- The financial statements are not in agreement with the accounting records and returns; or
- We have not received all the information and explanations we require for our audit.

## **RESPONSIBILITIES OF TRUSTEES**

As explained more fully in the Trustees' Responsibilities Statement, the trustees (who until 4th August 2022 were also the directors of charitable company (for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the Charitable Incorporated Organisation ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the Charitable Incorporated Organisation or to cease operations, or have no realistic alternative but to do so.

## **OUR RESPONSIBILITIES FOR THE AUDIT OF THE FINANCIAL STATEMENTS**

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation.

This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our Report of the Independent Auditors.

#### **USE OF OUR REPORT**

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

For and on behalf of Cooper Adams Ltd  
Chartered Accountants  
and Statutory Auditors  
12 Payton Street  
Stratford upon Avon  
Warwickshire  
CV37 6UA



---

David Cooper

# STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2023

	Notes	Unrestricted funds (£)	Restricted funds (£)	2023 Total Funds (£)	2022 Total Funds (£)
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and Legacies	2	423,127	495,215	918,342	834,596
Other trading activities	3	5,743	-	5,743	5,743
Investment income	4	588	-	588	130
<b>Total</b>		<b>429,458</b>	<b>495,215</b>	<b>924,673</b>	<b>839,420</b>
<b>EXPENDITURE ON</b>					
Raising funds	5	169,411	-	169,411	161,871
<b>CHARITABLE ACTIVITIES</b>					
	6				
Provision of support		157,878	443,691	601,569	379,520
Governance costs		64,973	-	64,973	68,228
Research related activity		20,686	884	21,570	105,847
<b>Total</b>		<b>412,948</b>	<b>444,575</b>	<b>857,523</b>	<b>715,466</b>
<b>NET INCOME</b>					
		16,510	50,640	67,150	123,954
Transfers between funds	17	(367)	367	-	-
Net movement in funds		16,143	51,007	67,150	123,954
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		548,837	40,327	589,164	465,210
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>564,980</b>	<b>91,334</b>	<b>656,314</b>	<b>589,164</b>

# STATEMENT OF FINANCIAL POSITION

31 March 2023

	Notes	Unrestricted funds (£)	Restricted funds (£)	2023 Total Funds (£)	2022 Total Funds (£)
<b>FIXED ASSETS</b>					
Tangible assets	12	7,037	-	7,037	8,116
<b>CURRENT ASSETS</b>					
Stocks	13	5,791	-	5,791	6,285
Debtors	14	36,117	-	36,117	15,239
Cash at bank and in hand		536,710	91,334	628,044	591,204
		578,618	91,334	669,952	612,728
<b>CREDITORS</b>					
Amounts falling due within one year	15	(20,675)	-	(20,675)	(31,680)
<b>NET CURRENT ASSETS</b>					
		557,943	91,334	649,277	581,048
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>					
		564,980	91,334	656,314	589,164
<b>NET ASSETS</b>					
		564,980	91,334	656,314	589,164
<b>FUNDS</b>					
	17				
Unrestricted funds:					
General fund				564,980	548,837
Restricted funds:					
General fund				91,334	40,327
<b>TOTAL FUNDS</b>				<b>656,314</b>	<b>589,164</b>

These financial statements have been audited under the requirements of Section 145 of the Charities Act 2011.

The financial statements were approved by the Board of Trustees and authorised for issue on 16/08/2023 and were signed on its behalf by:



K M Jackson - Trustee

16.08.2023



M T Dearlove - Trustee

16.08.2023

# STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2023

	Notes	2023 (£)	2022 (£)
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>			
Cash generated from operations	1	38,647	130,371
Cash generated from operations		38,647	130,371
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>			
Purchase of tangible fixed assets		(2,395)	(8,223)
Interest received		588	130
Net cash used in investing activities		(1,807)	(8,093)
<b>CHANGE IN CASH AND CASH EQUIVALENTS IN THE REPORTING PERIOD</b>		36,840	122,278
<b>CASH AND CASH EQUIVALENTS AT THE BEGINNING OF THE REPORTING PERIOD</b>		<u>591,204</u>	<u>468,926</u>
<b>CASH AND CASH EQUIVALENTS AT THE END OF THE REPORTING PERIOD</b>		<b><u>628,044</u></b>	<b><u>591,204</u></b>

## NOTES TO THE STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2023

### 1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2023 (£)	2022 (£)
<b>NET INCOME FOR THE REPORTING PERIOD (AS PER THE STATEMENT OF FINANCIAL ACTIVITIES)</b>	67,150	123,954
<b>ADJUSTMENTS FOR:</b>		
Depreciation charges	3,474	4,253
Interest received	(588)	130
Decrease/(increase) in stocks	494	(29)
Increase in debtors	(20,878)	(6,600)
(Decrease)/increase in creditors	<u>(11,005)</u>	<u>8,923</u>
<b>Net cash provided by operations</b>	<b>38,647</b>	<b>130,371</b>



**2. ANALYSIS OF CHANGES IN NET FUNDS**

	At 1.4.22 (£)	2023 (£)	2022 (£)
<b>NET CASH</b>			
(Decrease)/increase in creditors	591,204	36,840	628,044
	591,204	36,840	628,044
<b>TOTAL FUNDS</b>	<b>591,204</b>	<b>36,840</b>	<b>628,044</b>

# NOTES TO THE FINANCIAL STATEMENTS

## for the Year Ended 31 March 2023

### 1. ACCOUNTING POLICIES

#### BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

#### INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

#### EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

## TANGIBLE FIXED ASSETS

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Office equipment	- 10 - 20% on cost
Database	- 14.3% on cost
Computer equipment	- 25% on cost

## STOCKS

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

## TAXATION

The charity is exempt from corporation tax on its charitable activities.

## FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular purposes.

<b>2. DONATIONS AND LEGACIES</b>	2023 (£)	2022 (£)
Donations and gifts	759,199	680,272
Legacies	5,312	25,000
The National Lottery Community Fund	<u>153,831</u>	<u>129,324</u>
	<b>918,342</b>	<b>834,596</b>

<b>3. OTHER TRADING ACTIVITIES</b>	2023 (£)	2022 (£)
Merchandise sales	5,743	4,694

<b>4. INVESTMENT INCOME</b>	2023 (£)	2022 (£)
Bank interest	588	130

<b>5. RAISING FUNDS</b>	2023 (£)	2022 (£)
<b>RAISING DONATIONS AND LEGACIES</b>		
Staff costs	133,680	94,642
Fundraising and publicity	21,090	25,817
Events and promotions	12,304	38,702
Cost of merchandise sales	2,337	2,710
	<b>169,411</b>	<b>161,871</b>

<b>6. CHARITABLE ACTIVITIES COSTS</b>	2023 (£)	2022 (£)
<b>PROVISION OF SUPPORT</b>		
Staff costs and other expenses	373,414	277,712
Information and awareness raising	34,641	7,465
Shared experiences network	24,045	27,048
Outreach service	48,285	37,923
Welfare and equipment grants	121,184	29,372
	<b>601,569</b>	<b>379,520</b>
<b>RESEARCH RELATED ACTIVITY</b>		
Staff costs and other expenses	18,093	64,423
Medical research grants	-	35,072
Other research activities	3,477	6,352
	<b>21,570</b>	<b>105,847</b>

<b>7. SUPPORT COSTS</b>	2023 (£)	2022 (£)
Staff costs and other expenses	51,285	48,301
Professional fees and bank charges	6,478	8,939
Other costs	7,210	10,988
	<b>64,973</b>	<b>68,228</b>

<b>8. NET INCOME / (EXPENDITURE)</b>	2023 (£)	2022 (£)
Depreciation - owned assets	3,474	4,253
Fees payable to auditor for:		
Audit	1,750	1,500
Other services	3,450	3,265

## 9. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2023 nor for the year ended 31 March 2022.

### Trustees' expenses

There were no trustees' expenses reimbursed for the year ended 31 March 2023 (2022:£nil).

Payments in respect of trustee indemnity insurance amounted to £398 (2022: £398).

10. STAFF COSTS	2023 (£)	2022 (£)
Wages and salaries	461,860	391,466
Social security costs	43,784	34,664
Pension	20,476	17,288
	<b>526,120</b>	<b>443,418</b>
<b>THE AVERAGE MONTHLY NUMBER OF EMPLOYEES DURING THE YEAR WAS AS FOLLOWS:</b>	<b>2023</b>	<b>2022</b>
Management and administration	1	1
Direct charitable expenditure	10	10
Fundraising and publicity	5	5
	<b>16</b>	<b>16</b>

We also engaged contractors in 2023 to assist us with our management and administration 1.2 FTE.

No employees received emoluments in excess of £60,000 (2022: None)

## 11. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds (£)	Restricted funds (£)	Total Funds (£)
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	579,516	255,080	834,596
Other trading activities	4,694	-	4,694
Investment income	130	-	130
<b>TOTAL</b>	<b>584,340</b>	<b>255,080</b>	<b>839,420</b>
<b>EXPENDITURE ON</b>			
Raising funds	161,871	-	161,871
<b>CHARITABLE ACTIVITIES</b>			
Provision of support	153,498	226,022	379,520
Governance costs	68,228	-	68,228
Research related activity	95,847	10,000	105,847
<b>TOTAL</b>	<b>479,444</b>	<b>236,022</b>	<b>715,466</b>

	Unrestricted funds (£)	Restricted funds (£)	Total Funds (£)
<b>NET INCOME</b>	104,896	19,058	123,954
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	443,941	21,269	465,210
<b>TOTAL FUNDS CARRIED FORWARD</b>	<b>548,837</b>	<b>40,327</b>	<b>589,164</b>

<b>12. TANGIBLE FIXED ASSETS</b>	Office Equipment (£)	Database (£)	Computer Equipment (£)	Totals (£)
<b>COST</b>				
At 1 April 2022	2,554	31,312	18,468	18,468
Additions	-	-	2,395	2,395
<b>At 31 March 2023</b>	<b>2,554</b>	<b>31,312</b>	<b>20,863</b>	<b>54,729</b>
<b>DEPRECIATION</b>				
At 1 April 2022	1,391	31,312	11,515	44,218
Charge for year	159	-	3,315	3,474
At 31 March 2023	1,550	31,312	14,830	47,692
<b>NET BOOK VALUE</b>				
At 1 April 2023	1,004	-	6,033	7,037
At 31 March 2022	1,163	-	6,953	8,116

<b>13. STOCKS</b>	2023 (£)	2022 (£)
Stocks held for re-sale	5,791	6,285

<b>14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR</b>	2023 (£)	2022 (£)
Prepayments and accrued income	36,117	15,239

<b>CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR</b>	2023 (£)	2022 (£)
Social security and other taxes	14,555	14,869
Other creditors	921	3,810
Accrued expenses	5,199	13,001
	<b>20,675</b>	<b>31,680</b>

**16. LEASING AGREEMENTS**

2023 (£)

2022 (£)

Minimum lease payments under non-cancellable operating leases fall due as follows:

Within one year	20,094	21,150
Between one and five years	22,500	45,146
	<b>42,594</b>	<b>66,296</b>

**17. MOVEMENT IN FUNDS**

At 1.4.22 (£)

Net Movement in funds (£)

Transfer between funds (£)

At 31.3.23 (£)

**Unrestricted funds**

General fund	548,837	16,510	(367)	564,980
--------------	---------	--------	-------	---------

**Restricted funds**

Various	40,327	50,640	367	91,334
---------	--------	--------	-----	--------

<b>TOTAL FUNDS</b>	<b>589,164</b>	<b>67,150</b>	<b>-</b>	<b>656,314</b>
--------------------	----------------	---------------	----------	----------------

Net movement in funds, included in the above are as follows:

	Incoming resources (£)	Resources expended (£)	Movement in funds (£)
<b>Unrestricted funds</b>			
General fund	429,458	(412,948)	16,510
<b>Restricted funds</b>			
General fund	495,215	(444,575)	50,640
<b>TOTAL FUNDS</b>	<b>924,673</b>	<b>(857,523)</b>	<b>67,150</b>

**COMPARATIVES FOR MOVEMENT IN FUNDS**

	At 1.4.21 (£)	Net Movement in funds (£)	At 31.3.22 (£)
<b>Unrestricted funds</b>			
General fund	443,941	104,896	548,837
<b>Restricted funds</b>			
General fund	21,269	19,058	40,327
<b>TOTAL FUNDS</b>	<b>465,210</b>	<b>123,954</b>	<b>589,164</b>

	Incoming resources (£)	Resources expended (£)	Movement in funds (£)
<b>Unrestricted funds</b>			
General fund	584,340	(479,444)	104,896
<b>Restricted funds</b>			
General fund	255,080	(236,022)	19,058
<b>TOTAL FUNDS</b>	<b>839,420</b>	<b>(715,466)</b>	<b>123,954</b>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.4.21 (£)	Net Movement in funds (£)	Transfer between funds (£)	At 31.3.23 (£)
<b>Unrestricted funds</b>				
General fund	443,941	121,406	(367)	564,980
<b>Restricted funds</b>				
Various	21,269	69,698	367	91,334
<b>TOTAL FUNDS</b>	<b>465,210</b>	<b>191,104</b>	<b>-</b>	<b>656,314</b>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources (£)	Resources expended (£)	Movement in funds (£)
<b>Unrestricted funds</b>			
General fund	1,013,798	(892,392)	121,406
<b>Restricted funds</b>			
General fund	750,295	(680,597)	69,698
<b>TOTAL FUNDS</b>	<b>1,764,093</b>	<b>(1,572,989)</b>	<b>191,104</b>

<b>STATEMENT OF FUNDS</b>	Balance b/f at 1.4.22 £	Incoming Resources £	Resources Expended £	Funds Transfer £	Balance c/f at 31.3.23 £
<b>Unrestricted funds</b>					
General funds	548,837	429,458	(412,948)	(367)	564,980
<b>Restricted funds</b>					
Support into the 2020s:					
- Lotteries Reaching Communities	28,669	-	(28,669)	-	-
- Other Grants	10,000	-	(10,000)	-	-
Toy Packs	350	500	(350)	-	500
Flexible Response Grants	-	-	(200)	200	-
Support Work with Families in Scotland	-	500	(500)	-	-
UK SMA Newborn Screening Alliance	-	106,734	(101,335)	-	5,399
SMA Horizons Project	-	1,080	(317)	-	763
Working with the SMA Community through Covid & Beyond - England	-	153,831	(85,432)	-	68,399
Working with the SMA Community through Covid & Beyond - UK	-	150,000	(150,000)	-	-
Website & Digital Comms Development	-	57,570	(51,297)	-	6,273
Support Services	-	15,000	(15,000)	-	-
PhD Scholarship Yr2	-	10,000	-	-	10,000
Northern Ireland Events	1,308	-	(1,475)	167	-
<b>TOTAL RESTRICTED FUNDS</b>	<b>40,327</b>	<b>495,215</b>	<b>(444,575)</b>	<b>367</b>	<b>91,334</b>
<b>TOTAL FUNDS</b>	<b>589,164</b>	<b>924,673</b>	<b>(857,523)</b>	<b>-</b>	<b>656,314</b>

## ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds (£)	Restricted funds (£)	Total Funds (£)
<b>Fund balances at 31 March 2023 are represented by:</b>			
Tangible fixed assets	7,037	-	7,037
Stock	5,791	-	5,791
Debtors	36,117	-	36,117
Bank and cash	536,710	91,334	628,044
Current liabilities	(20,675)	-	(20,675)
<b>TOTAL NET ASSETS</b>	<b>564,980</b>	<b>91,334</b>	<b>656,314</b>

### Support into the 2020s

This includes many of the services and workstreams described in the section, 'Achievements and Performance': information production, outreach, support and advocacy work and the organising of community networks and events and advocacy.

It is funded by :

### Lotteries Reaching Communities

This is a 3 year grant (June 2019 – May 2022) to cover 50% of the costs of our 'Support into the 2020s services in England.

### Support into the 2020s-Other

Combines donations from Trusts and restricted community donations towards the remaining costs across the UK.

### Toy Packs

Our multi-sensory toy packs are available free of charge to families in the UK for newly diagnosed children. They include items that provide visual, tactile and auditory stimulation. They have been designed to offer entertainment during the day, fun at bath time and comfort at bedtime. They are suitable for infants aged up to 12 months of age.

### Flexible Response Grants

This fund provides a swift response to an urgent need when no other funding source is available. It may also assist people with travel and subsistence costs when they access treatments. Grants are typically small.

### Support with Families in Scotland

A fund that helped to cover the costs of our support work in Scotland.



### **UK SMA Newborn Screening Alliance**

The Alliance brings together clinicians, patient groups and other stakeholders, determined to achieve the earliest possible introduction of newborn screening for SMA in the UK and in so doing deliver the best outcomes from treatment and reduce future healthcare costs. This fund supports the costs of the Project Manager, the secretariat (SMA UK and MDUK) and communications.

### **SMA Horizons Project**

The SMARt Horizon project has the goal to identify new innovation, 'out of the box' therapies for people living with SMA, especially for the chronic population. These therapies may be complementary to the existing ones that target the SMN upregulation.

### **Working with the SMA Community Through Covid & Beyond- England**

This Fund, provided by the National Lotteries, supports our information, outreach and support, community development and advocacy services. The 2022/3 grant was the first year of a 4 year grant (September 2022 - August 2026) making a significant contribution to the costs of these services. Contributions from Lotteries will reduce over the 4 year period.

### **Working with the SMA Community Through Covid & Beyond-UK**

This Fund goes towards the costs of our information, outreach and support, community development and advocacy services that are not covered by the National Lotteries grant.

### **Website & Digital Comms Development**

This year this fund was set up to enable the launch of a new website and branding refresh targeted for August 2023. It also increased our Communications staffing capacity, our communications reach and supported the further development of community virtual networks.

### **Support Services**

This fund targeted any Support Services costs that were not covered by any of the other restricted funds that support this work.

### **Northern Ireland Events**

This fund enables us to offer events in Northern Ireland for adults, children and young people with SMA and their families. These provide opportunities to share experiences and connect up with others in the SMA Community.

**PhD Scholarship Yr2**

This supports our commitment to fund the 4-year research programme that aims to further understand the motor enlargement process in people who have SMA and how this might be addressed and improve treatment outcomes. It runs from 2022-2025, and is funded jointly with Muscular Dystrophy UK.

**18. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 31 March 2023.

**19. CHARITY STRUCTURE**

On 4th August 2022 the charity changed from a 'company limited by guarantee' to a 'charitable incorporated organization'.

# DETAILED STATEMENT OF FINANCIAL ACTIVITIES

**for the Year Ended 31 March 2023**

	2023 (£)	2022 (£)
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and gifts</b>		
Donations and gifts	759,199	680,272
Legacies	5,312	25,000
The National Lottery Community Fund	153,831	129,324
<b>Other trading activities</b>		
Merchandise sales	5,743	4,694
<b>Investment income</b>		
Bank interest	588	130
<b>TOTAL INCOMING RESOURCES</b>	<b>924,673</b>	<b>839,420</b>
	2023 (£)	2022 (£)
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Staff costs and other expenses	133,680	94,642
Fundraising and publicity	21,090	25,817
Events and promotions	12,304	38,702
Cost of merchandise sales	2,337	2,710
	<b>169,411</b>	<b>161,871</b>

	2023 (£)	2022 (£)
<b>Charitable activities</b>		
Staff costs and other expenses	391,507	342,135
Medical research grants	378	35,072
Other research activities	3,099	6,352
Information and awareness raising	34,641	7,465
Shared experiences network	24,045	27,048
Outreach service	48,285	37,923
Welfare, equipment grants and toy packs	121,184	29,372
	<b>623,139</b>	<b>485,367</b>
<b>Support costs</b>		
<b>Management</b>		
Staff costs and other expenses	51,285	48,301
Professional fees and bank charges	6,478	8,939
Other costs	7,210	10,988
	<b>64,973</b>	<b>68,228</b>
<b>TOTAL RESOURCES EXPENDED</b>	<b>857,523</b>	<b>715,466</b>
<b>NET INCOME</b>	<b>67,150</b>	<b>123,954</b>



Address: Unit 9, Shottery Brook Office Park. Timothy's Bridge Road,  
Stratford-Upon-Avon, Warwickshire, CV37 9NR  
[Office@smauk.org.uk](mailto:Office@smauk.org.uk) | 01789 267520

Registered Charity Number 1106815