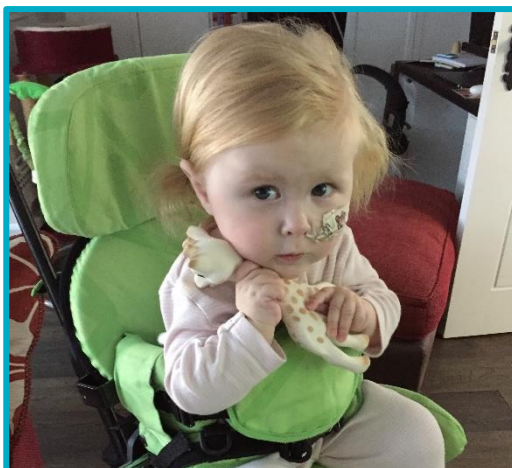


# Annual Report & Financial Statements

For the year ending 31<sup>st</sup> March 2020



## Welcome to our Annual Report and Financial Statements

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### Partnerships & Affiliations

We are pleased to continue working with many groups, including:



## Letter from the Chair

The twelve months to 31st March 2020 have been an extraordinary time for the SMA Community and for SMA UK with much changed, accomplished and, as ever, left to do.

2019 / 20 was a landmark year for the SMA Community when, in July 2019, NHS funding agreements for access to the drug treatment nusinersen (Spinraza™) were announced. Although we were delighted to at last see a positive outcome for many, we were devastated to see in England the exclusion of the large majority who have SMA Type 3. We immediately started work to advocate for change and to monitor the reality of how soon children and adults would actually receive treatment. This has remained a top priority.

I was also extremely proud to see two other substantial SMA UK specific accomplishments this year. We were very pleased to have been a very active member of the international group that worked on the Guide to the International Standards of Care for SMA project and were grateful to all the people in the community who so generously allowed us to pass on their photos to enrich the UK version.

We also launched the 'Living With SMA' section of the website. This promises to be a hugely useful resource and one that the SMA UK team will work to develop further with the wider community. While this and the rest of our website, with its wide range of information including developments in research and treatments, is very public, our one-to-one confidential outreach and support service continues quietly providing our invaluable work with individual families and adults.

Another very public part of our work is our great tradition of providing face-to-face information, support and social events. This year we began planning a very ambitious two-year programme with the first meeting scheduled for August 2020. Obviously Covid changed everything but we remain ready to re-launch when conditions allow. In the meantime, our virtual community networks remain very active and have been enhanced with the

launch of our Community Connections Project, offering social events and interactive information sessions covering a wide range of topics.

We have also reviewed, updated and recommitted to the SMA UK strategy objectives that are detailed on the next page. Extremely ambitious as ever and although we've made excellent progress, there is much further to go, not least to achieve our research ambitions.

I would like to thank the retiring Trustees - you've all been exceptional and individually given so much to our cause. All of your time, energy, insight, advice and in particular some with your exceptional fundraising contributions and others with your financial control and analysis! We are very much in your debt but delighted that you continue to support us in a myriad of ways.

A big thank you also to our new Trustees, not least for seamlessly taking the baton from the retirees. Special thanks to Mark Dearlove, who has taken over from me as Chair in the eye of the Covid storm and has provided great leadership and dedicated much time in a most testing environment.

Last but not least, I would like to thank from the bottom of my heart the quite incredible team that is SMA UK. With the tireless and exceptional leadership of Liz Ryburn, Support Team Manager, and Caroline Dolan, Fundraising Manager, you've together accomplished so much in very testing circumstances. SMA UK is in robust financial and operational health thanks to your amazing and greatly appreciated dedication.

Thank you.



**Hugo van Vredenburg**  
Chairman

## Trustees' Strategic Report

Spinal Muscular Atrophy (SMA) is a rare, genetically inherited neuromuscular condition affecting children, young people and adults. It causes progressive muscle weakness and loss of movement due to muscle wasting (atrophy). This may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. The impact and severity of SMA varies greatly.

It is thought that there are between 670 – 1340 children, young people and adults, who have SMA living in the UK. It is estimated that some 73 babies born each year will have some form of SMA.

### Our Charity

The Jennifer Trust for SMA was founded in 1985. In April 2014, it became Spinal Muscular Atrophy Support UK. The SMA Trust was set up in 2003. In 2018, the two merged as Spinal Muscular Atrophy UK.

### Our Vision

Everyone affected by SMA has access to the best care, support and drug treatments; research continues to bring breakthroughs that improve people's quality of life, and ultimately aims to find a cure.

### Our Mission

To provide accurate information and a wide range of support services, while working to improve access to the best care, services and drug treatments today and funding

research projects that can change tomorrow.



### 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 disability and obtaining the right support, care and opportunities to enable them to live long and fulfilling lives; some face the distress of early bereavement.



## Our Strategy

### Providing Information and Support Services in the UK for:

- families and individuals – personalised information about SMA; emotional and practical support; advocacy for services and access to care and drug treatments; opportunities to have contact with others affected by the condition.
- health, education and social care professionals – information about SMA; working with them to support families and individuals.
- the SMA Community - up-to-date information about developments in research, drug treatments, support and disability services, consultations and campaigns.

### Working to Improve and Monitor SMA Community Access to:

- care and support
- clinical trials and new drug treatments
- equipment and adaptations

We are **advocates** on behalf of the SMA Community to authorities that regulate access to drug treatments, care and services. We work with other charities, health, education and social care professionals, national and international charities, and organisations to **campaign** on issues that matter to people affected by SMA. We **support**

**developments** that improve and monitor access to services and drug treatments.

### Funding and Supporting Research:

Pharmaceutical companies are now investing heavily in the clinical development of drug treatments; these are important stepping stones that we will continue to monitor and support. Our funding focus will now be on projects that contribute to:

- understanding the complexities of SMA and the underlying disease mechanisms.
- the pre-clinical development of drug treatments.
- improvements in the clinical care and management of people affected by SMA.
- continuing to support, strengthen and develop the capacity of the UK SMA scientific and clinical community.

Our excellent track record of raising and delivering money to the scientific community, along with our strong connections and collaborations with clinicians, researchers, international groups and the pharmaceutical industry, ensure we are not duplicating efforts when we fund and support initiatives that will ease the path to drug treatments and improvements in clinical care.

**Where we can make a difference,  
we will.**

## Achievements and Performance

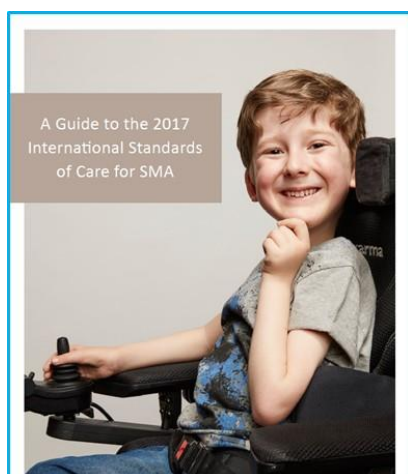
### Who delivers our services?

We have a small Support Services Team of experienced staff (Claire, Maggie, Michele, Jackie and Jo - 4.3 full-time equivalent) with backgrounds in social work, nursing, occupational therapy, mental health and education, working with our Support Services Manager, Liz, and Libby, our Communications & Support Coordinator.

We also have fantastic networks of more than 150 adults, young people and parents in the SMA Community who are always willing to review our information, answer questions and offer their experiences, tips and advice.

Our Research Correspondents fulfil their commitments to us on top of their other work and roles: James leads his own laboratory research team, Alex is an NHS paediatrician, and Vanessa is also the SMA Europe Coordinator.

### Information



This year we were heavily involved in writing the family version of the Guide to the

International Standards of Care for SMA, along with Treat-NMD and other groups. We were delighted to be able to provide all the photos for the UK edition, with the willing agreement of everyone in them.

In August, following a mammoth amount of preparation, we launched our new website section, 'Living With SMA', which was visited by nearly 1,200 people by the end of 2019. Divided into three main sections for parents of children, teenagers and adults, it builds on knowledge and advice from the SMA Community and SMA UK's Support Services Team. It covers a whole host of topics including; health & wellbeing, equipment, homes, education, work, transport, leisure, holidays, financial, emotional and social support:



[www.livingwithsma.org.uk](http://www.livingwithsma.org.uk)

*"This is really well put together and looks good, excellent work."*

**Rosaline Quinlivan, Professor of Neuromuscular Disease, University College London.**

During the year, some 67,800 people accessed our website as a whole. The Information, Support, and Treatment & Research-related pages in the top ten website page views were:

Page name	Total views 2019
SMA Information	6,764
Support	3,866
About SMA	3,676
Nusinersen	3,488

We also produced our bi-annual newsletter ‘SMA Matters’ and our monthly E-news bulletin. E-news covers services and research updates, campaigns and surveys, social and fundraising events, and other general information and news. By the end of the year, this was going to more than 2,900 people, with a 26.3% opening rate (benchmark for similar mailings across the sector are 21%). In October, we took a snapshot of our social media reach as we also use these channels to connect with the Community:

	October
Facebook likes	4,458
Twitter followers	1,694
Instagram followers	678

With so many different ways of being in touch and not always knowing who we are reaching, it’s difficult to know exactly how many have SMA and are in the UK. Our best conservative estimate, based on our mailing list, is that we are in contact with some 600 households where there is a parent of a child / young person who has

SMA or an adult who has SMA. Similarly, we are in contact with more than 340 families bereaved by SMA.

We are members of the UK-wide SMA REACH clinical network of professionals from specialist centres where children, young people and adults are diagnosed, and that provide ongoing care. We make sure to keep all these centres up-to-date with what we offer and provided them with packs of information guides, “postcards” and leaflets about our services.

### Outreach

In the UK in 2019, we supported 232 children, young people and adults who have SMA, and their families, via phone, email and home visits. Every person’s circumstances, requests and needs are different - from emotional support, practical advice and guidance for a family following the devastating news of their child’s diagnosis, to assisting an adult with presenting their case when their care and support funding package is being reviewed.



*“Thank you for answering the myriad of questions we have had about SMA and our future going forward. And thank you also for supporting members of our family.”*  
**Parent of a newly diagnosed child.**

*“Our first contact was when our daughter was diagnosed. You visited and sat with us for hours telling us all about SMA. We can go weeks, months or even years without needing to get in touch but the moment we do, you are at the end of the phone and will always go over and above to help in any way you can. Without the Outreach Service you provide, so many families would feel alone with nowhere to turn.”*

**Parent of young teenager.**

*“Thank you so much for the support letter, we would have been lost without you guys.”*

**Parent negotiating health and social care support as their son moves to adult services.**

*“Thank you so much for your reply – it is very useful! I will let you know how I get on with everything.”*

**Young adult enquiring about learning to drive.**

The team also supported over 90 health, education and social care professionals in their work with people who have SMA.

*“Thank you so much for your comprehensive response – this is super useful!”*

**Neuromuscular Team Member re: car seats and buggies information.**

Though we focus on the UK, we always reply to overseas enquiries - so often to families desperately seeking treatment. We do our best to link people in to support networks and give relevant information.

### **Multisensory Toy Packs**

This year we sent out 21 multisensory toy packs suitable for infants aged up to 12

months of age, who have SMA and are living in the UK.



*“...a great big huge thank you for her new toys, she loves them...you have been just so kind and supportive.”*

**Mum of a child who has SMA Type 1.**

### **Shared Experiences: Virtual Networks**

As SMA is a rare condition, the all too important opportunities for individuals and families affected by SMA to have contact, share experiences and support each other, can be difficult to achieve.

Our **Adult Insight Group (AIG)** is well established and is both a support network and important sounding board for adults who have SMA and for SMA UK as well. Its 50 members (across a range of ages and backgrounds) who live across the UK, discuss a variety of topics in their Facebook group and quarterly video calls: from physical and mental health; to accessing and maintaining equipment; finances; sex and relationships; leisure and tourism; employment and more.

*“To learn and grow from each other, to share the ups and downs where others understand and give support and courage. Love this group.”*

**AIG member**



We also have an ‘**Ask a Question Network**’ of 54 people aged 18+ affected by SMA who are keen to share what has worked for them, their tips and ideas. We email out the questions that come to us and if anyone has a response they think might help, they can email back. Also, in our **SMA Voices** people of all ages talk about their experiences.

For more on these services, see: [www.smauk.org.uk/connect-with-others](http://www.smauk.org.uk/connect-with-others)

### Shared Experiences: Face-to-Face Events

In April 2019, around 40 people attended a relaxed, social afternoon event for those affected by SMA, in Stirling, Scotland.

*"We had a fab day at the event and my son loved whizzing around with his wee friends!"* **Parent**



Following the success of our April 2018 Information, Support & Social Weekend, held in the Midlands, we realised that it was becoming impossible to find a suitable

venue that could also offer safe accessible accommodation for such huge numbers.

This helped us review what we could offer in the future and October 2019 therefore saw the beginning of plans for a two-year programme with Family Days in different regions and a biannual weekend for adults, that would also include a Family Day, in August 2020.



The first of these days in the autumn was attended by 70 individuals and included the opportunity to meet members of the Young Adults Network who shared their experiences of living with SMA.



*"Thank you for providing such an informative afternoon with the young people."* **Parent**

## Speaking Up For SMA

We continued to let the SMA Community know about campaigns, consultations and surveys. Three young people took up the challenge to speak up for SMA and attended a reception at the House of Commons, organised by Trailblazers from MDUK, on the Employability of Disabled People.

Advocacy for **access to drug treatments** has been our biggest 'Speaking up for SMA' challenge. We continued to work collaboratively with TreatSMA and MDUK to monitor the roll out of programmes for nusinersen treatment.



This included identifying individual children and geographical areas where there were access challenges, working with clinicians and NHS England to address these, and preparing to focus on access for adults in 2020. We also continued to advocate for access for the children and adults who have SMA Type 3 and don't have access in England, and the group of children who have SMA Type 3 whose continued access to treatment depends on their regaining the ability to walk 5 steps unaided.

This year saw other significant developments with potential treatments with the National Institute of Health and

Care Excellence (NICE) starting its appraisal of the clinical and cost-effectiveness of the gene therapy onasemnogene abeparvovec, trademarked Zolgensma™.



The Patient Groups surveyed the Community for views and made submissions urging for this treatment to be funded by the NHS once it is licensed for marketing by the European Medicines Agency (EMA).



We also closely followed the progress of clinical trials for risdiplam and its progress toward applications to regulatory authorities.

In 2018, our submission to the UK National Screening Committee (NSC) called for newborn screening for 5q SMA. In February 2019, this was not recommended by the NSC. We are now working with a wide network of groups to prepare for a further submission. We also worked with

Genetic Alliance UK to call for a reform of the screening review system and criteria.

We attended a number of parliamentary meetings and worked with a wide range of other groups, all of whom consider that when it comes to rare disease treatments, there are significant shortcomings in the current system in England. This included supporting Genetic Alliances UK's 'Action for Access' Campaign.

For more information on all these topics:

[www.smauk.org.uk/treatments-research](http://www.smauk.org.uk/treatments-research)

## Research Grants

Over the last 35 years we have raised and donated £5million in support of research into ground-breaking findings and initiatives that have been key to the development of drug treatments and access to clinical trials. This year we made contributions to:

### ➤ The UK SMA Research Consortium

This UK-wide collaborative network is led by Principal Investigators: Professor Kevin Talbot and Professor Tom Gillingwater. It consists of 7 world-class research teams based in Oxford, Edinburgh, Keele, Sheffield and London, working collaboratively across 4 main areas:

- Exploring the ways in which SMA affects different organs / systems within the body and which might be targets for treatments.
- Looking at what treatments could be beneficial if used in combination with

current SMN-boosting drugs like nusinersen (Spinraza™).

- Developing models to test out potential treatments.
- Looking at new methods of drug delivery, including in the womb.

### ➤ The UK SMA Patient Registry

This important database links adults and children who have SMA with researchers conducting studies, including clinical trials of new drug treatments.

### ➤ Keele University Study

Led by Dr Melissa Bowerman, this study seeks to assess whether a commercially available drug targeting metabolism could be a potential treatment for SMA, when given in combination with a gene therapy.

### ➤ Future Grants

We announced that grants over the next five years would only be for SMA-related PhD studentships in partnership with MDUK and contributions to SMA Europe's next call in 2022 to fund research that is peer reviewed and selected by the SMA Europe Scientific Advisory Board.

## International Collaboration

### ➤ SMA Europe Membership

We remained active members of this umbrella organisation of SMA patient and research groups. With 19 member countries, it is a vital advocacy network.



## Thank you to the Community

We're incredibly grateful for the support we receive from the SMA Community and our corporate and charitable trust supporters. The generosity and kindness of every donor enables the charity to continue having a positive impact on the lives of people affected by SMA.

In 2019 we watched our biggest team yet take on the Great North Run. This 35 strong team from across the UK took on the world-famous half-marathon and raised £15,000!

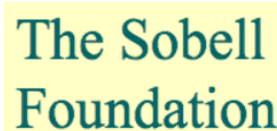
In addition, SMA UK's own fundraising events boosted funds significantly in 2019; events included Ride Scorpion, The National Gallery Dinner, and Manchester Business Lunch. We are grateful to all who attended and gave generously, and to our Trustees who were key to the events' success.

2019 saw our most successful Big Give Christmas Challenge campaign to date, with over £30,000 raised. Our thanks, as always, to the Community for getting behind this campaign and we look forward to continuing working together in 2020 / 21.



## Thank you to Trusts and Companies

Thank you to all the Trusts and organisations that have continued to support SMA UK, including:



## **Report of the Trustees for the year ended 31 March 2020**

The Trustees who are also directors of the Charity for the purposes of the Companies Act 2006, present their report with the financial statements of the Charity for the year ended 31 March 2020. 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 Aims**

As stated in its Memorandum and Articles of Association, Spinal Muscular Atrophy UK is established for:

- the relief of people living with Spinal Muscular Atrophy and related medical conditions;
- the relief of persons who are in need after experiencing a bereavement or loss due to Spinal Muscular Atrophy;
- the promotion of research into the causes and treatment of Spinal Muscular Atrophy.

### **Structure, Governance & Management**

#### **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.

### **Achievements and Performance**

See pages 6 - 11.

## **Future Plans**

This year we updated our strategy which you can find on pages 4 – 5; this includes how we hope to support research. We will continue to advocate for access to the new drug treatments (pg.10) and to represent the views of the SMA Patient Community to regulatory authorities and pharmaceutical companies. We will continue to provide our information and outreach services and offer opportunities for people in the Community to connect with each other. In the light of the Covid-19 pandemic starting to impact heavily on the SMA Community and our capability, we will need to smartly adapt what we do and how we do it.

## **Financial Review**

### **Financial Position**

See page 16 Treasurer's Report.

### **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 of general (core) overheads will be recovered against those reserves. The percentage recovery rate 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.

### **Governing Document**

The Charity is governed by its Memorandum and Articles of Association and constitutes a company limited by guarantee.

### **Appointment of Trustees**

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

### **Organisational structure**

All policy, strategy and financial decisions relating to the Charity have to be formally approved by the Board of Directors. The Board meets six times a year on a bi-monthly basis. Three of these meetings are held at the charity's offices in Stratford-upon-Avon, alternating with meetings held by telephone conferencing.

### **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.

### **Trustees' Responsibility Statement**

The Trustees (who are 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 company 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 company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company 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 company's 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.

**REFERENCE AND ADMINISTRATIVE DETAILS**

<p><b>Registered Company number</b></p> <p>05137534 (England and Wales)</p>	<p><b>Registered Charity number</b></p> <p>1106815</p>
<p><b>Registered office</b> – Unit 9 Shottery Brook Office Park, Timothy’s Bridge Road, Stratford-upon-Avon, CV37 9NR</p> <p><b>Formerly:</b> 40 Cygnet Court, Timothy’s Bridge Road, Stratford-upon-Avon, Warwickshire, CV37 9NW</p>	
<p><b>Trustees</b></p> <p>N A Ashby (resigned 1.9.19), M E Fenton, Dr H Sobati, T Clarke (resigned 1.11.19), H H C Van Vredenburch, Mrs T J Rice (resigned 1.9.19), T J D Sheffield, C S B Knight, T Woodward (resigned 1.9.19), J M Dee (resigned 27.1.20), Mrs D J Waltier, Dr R Quinlivan, T J Mildon (appointed 23.4.19), M T Dearlove (appointed 3.3.20), K M Jackson (appointed 4.9.19)</p>	
<p><b>Company Secretary</b></p> <p>Mrs E Ryburn</p>	
<p><b>Auditors</b></p> <p>Cooper Adams Ltd, Chartered Accountants and Statutory Auditors, 12 Payton Street, Stratford-upon-Avon, Warwickshire, CV37 6UA</p>	
<p><b>Chair</b></p> <p>M T Dearlove</p>	<p><b>Patrons</b></p> <p>Professor V Dubowitz</p>

Report of the Trustees, incorporating a strategic report, approved by order of the board of Trustees, as the company directors, on **26<sup>th</sup> November 2020** and signed on the Board's behalf by:



.....  
**M T Dearlove - Trustee**

## Treasurer's Report

This is the first full year of operation for SMA UK. Following the merger of Spinal Muscular Atrophy Support with The SMA Trust.

Income for the year was £925k, an increase of nearly 16% over the prior year. This was driven by Community and Trustee events. The charity also benefited from lottery funding, trust and pharmaceutical support.

Our 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 and reduced wherever possible. Year-on-year fundraising expenditure has increased in order to support the hugely successful fundraising event at the National Gallery. The cost of providing our charitable activities decreased by 7% year-on-year due to a reduction in information, support and social events. Governance or management costs have increased £17k year-on-year due to restructuring which has reduced expenditure going forward.

The percentage of our costs that was spent on our charitable purpose, our value in the pound, fell from 67p to 56p as resources were conserved at the end of the year so as to ensure that the charity can withstand the impact of the Covid pandemic on its fundraising and other income sources.

Our result for 2019 / 20 was a surplus of £78k compared to £35k in the prior year. The charity has built on the success of the merger to provide excellent service and ensure a stronger position for fundraising and an efficient cost base for the future. However, at the beginning of 2020 / 21 financial year, we have had to deal with the impact of the Covid pandemic.

SMA UK has taken a number of steps to respond to the impact of the pandemic which has significantly reduced fundraising due to the fact that Community in person events are not possible:

- The fundraising team has worked tirelessly to continue fundraising, focusing on Trusts and supporting virtual events.

- Reduced community support as in person visits have been curtailed.
- The charity has cut back on staff expenditure where possible and taken advantage of Government furlough and Covid support schemes.
- The charity has moved to new, more cost-effective premises and renegotiated office infrastructure contracts.
- The Board has been monitoring cash flow projections carefully and have ensured that expenditure is as controlled as possible whilst continuing our charitable purpose and supporting the Community at this difficult time.
- Cash resources are sufficient to sustain the charity within its reserves policy and on this basis the accounts are prepared on a going concern basis.

As a new Trustee, it has been exciting to take over from Neil Ashby and to help the charity with the challenges ahead.



**Katharine Jackson**  
Treasurer



## **Auditor's Report**

### **Report of the Independent Auditors to the Members of SMA UK**

We have audited the financial statements of Spinal Muscular Atrophy UK (the 'charitable company') for the year ended 31 March 2020 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 company's affairs as at 31 March 2020 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'; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### **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 company 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**

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

### **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 there is a material misstatement in the financial statements or a material misstatement of the other information. 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.

### **Opinions on other matters prescribed by the Companies Act 2006**

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

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

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate

for our audit have not been received from branches not visited by us; or

- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; 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 are also the directors of the 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 company's 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 company or to cease operations, or have no realistic alternative but to do so.

### **Our responsibilities for the audit of the financial statements**

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.

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 charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members 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 charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

David Cooper FCA  
(Senior Statutory Auditor)  
for and on behalf of Cooper Adams Ltd

Chartered Accountants  
and Statutory Auditors  
12 Payton Street  
Stratford-upon-Avon  
Warwickshire  
CV37 6UA



Date: 1 December 2020

**Spinal Muscular Atrophy UK**  
**STATEMENT OF FINANCIAL ACTIVITIES for the Year Ended 31 March 2020**

	Notes	Unrestricted Funds £	Restricted Funds £	2020 Total Funds £	2019 Total Funds £
<b>INCOME &amp; ENDOWMENTS FROM</b>					
Donations & Legacies	2	745,530	174,303	919,833	790,306
Other trading activities	3	5,262	-	5,262	4,386
Investment income	4	775	-	775	6,126
<b>Total</b>		<u>751,567</u>	<u>174,303</u>	<u>925,870</u>	<u>800,818</u>
<b>EXPENDITURE ON</b>					
Raising funds	5	267,390	-	267,390	163,831
<b>Charitable activities</b>	6				
Provision of support		155,189	192,197	347,386	385,868
Pursuit of knowledge		115,189	8,750	123,939	124,066
Governance costs		109,102	-	109,102	92,255
<b>Total</b>		<u>646,870</u>	<u>200,947</u>	<u>847,817</u>	<u>766,020</u>
<b>NET INCOME/(EXPENDITURE)</b>		104,697	(26,644)	78,053	34,798
<b>Transfers between funds</b>	16	<u>(18,766)</u>	<u>18,766</u>		
<b>Net movement in funds</b>		85,931	(7,878)	78,053	34,798
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		212,768	25,040	237,808	203,010
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u>298,699</u>	<u>17,162</u>	<u>315,861</u>	<u>237,808</u>

The notes form part of these financial statements

**Spinal Muscular Atrophy UK**  
**Statement of Financial Position at 31 March 2020**

	Notes	Unrestricted Funds £	Restricted Funds £	2020 Total Funds £	2019 Total Funds £
<b>FIXED ASSETS</b>					
Tangible assets	11	6,113	-	6,113	10,838
<b>CURRENT ASSETS</b>					
Stocks	12	7,835	-	7,835	2,570
Debtors	13	42,191	-	42,191	48,244
Cash at bank and in hand		280,322	17,162	297,484	214,679
		<u>330,348</u>	<u>17,162</u>	<u>347,510</u>	<u>265,493</u>
<b>CREDITORS</b>					
Amounts falling due within one year	14	(37,762)	-	(37,762)	(38,523)
<b>NET CURRENT ASSETS</b>		<u>292,586</u>	<u>17,162</u>	<u>309,748</u>	<u>226,970</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		298,699	17,162	315,861	237,808
<b>NET ASSETS</b>		<u>298,699</u>	<u>17,162</u>	<u>315,861</u>	<u>237,808</u>
<b>FUNDS</b>					
Unrestricted funds: General fund	16			298,699	212,768
Restricted funds: Various – see note 16				17,162	25,040
<b>TOTAL FUNDS</b>				<u>315,861</u>	<u>237,808</u>

The financial statements were approved by the Board of Trustees and authorised for issue on **26<sup>th</sup> November 2020**

..... and were signed on its behalf by:



.....  
**K M Jackson – Treasurer**



.....  
**M T Dearlove – Trustee**

The notes form part of these financial statements

**Spinal Muscular Atrophy UK**  
**Statement of Cash Flows for the Year Ended 31 March 2020**

	Notes	2020 £	2019 £
<b>Cash flows from operating activities:</b>			
Cash generated from operations	1	83,135	91,521
<b>Net cash provided by operating activities</b>		<b>83,135</b>	<b>91,521</b>
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		(1,105)	(9,101)
Dividends received		775	6,126
Net cash provided used in investing activities		(330)	(2,975)
<b>Change in cash and cash equivalents in the reporting period</b>		<b>82,805</b>	<b>88,546</b>
<b>Cash and cash equivalents at the beginning of the reporting period</b>		<b>214,679</b>	<b>126,133</b>
<b>Cash and cash equivalents at the end of the reporting period</b>		<b><u>297,484</u></b>	<b><u>214,679</u></b>

**Notes to the Statement of Cash Flows**  
**For the Year Ended 31 March 2020**

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

	2020 £	2019 £
<b>Net income for the reporting period (as per the Statement of Financial Activities)</b>	78,053	34,798
<b>Adjustments for:</b>		
Depreciation charges	5,830	11,315
Dividends received	(775)	(6,126)
(Increase)/decrease in stocks	(5,265)	5,539
Decrease in debtors	6,053	26,813
(Decrease)/increase in creditors	(761)	19,182
<b>Net cash provided by operations</b>	<b><u>83,135</u></b>	<b><u>91,521</u></b>

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

	At 1.4.19 £	Cash flow £	At 31.3.20 £
<b>Net Cash</b>	214,679	82,805	297,484
Cash at bank and in hand			
	214,679	82,805	297,484
Total	214,679	82,805	297,484

The notes form part of these financial statements

## 1. ACCOUNTING POLICIES

### Basis of preparing the financial statements

The financial statements of the charitable company, 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 Companies Act 2006. 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:

Improvements to property	20% on cost
Office equipment	10 – 20% on cost
Database	14.3 % on cost
Computer equipment	25%

### Stocks

Stocks are valued at the lower 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.

**Spinal Muscular Atrophy UK**  
**Notes to the Financial Statements for the Year Ended 31 March 2020 - continued**

**2. DONATIONS AND LEGACIES**

	<b>2020</b> <b>£</b>	<b>2019</b> <b>£</b>
Donations and gifts*	795,531	547,863
Legacies	-	200
SMA Trust fund donation	-	176,125
Lotteries – Reaching Communities	124,302	66,118
	<b>919,833</b>	<b>790,306</b>

(\*6.6% of total income was in the form of grants from pharmaceutical companies to support service delivery: Novartis 10,000; Roche 26,000; Sanofi Genzyme 25,000)

**3. OTHER TRADING ACTIVITIES**

	<b>2020</b> <b>£</b>	<b>2019</b> <b>£</b>
Merchandise sales	5,262	4,208
Rental income	-	178
	<b>5,262</b>	<b>4,386</b>

**4. INVESTMENT INCOME**

	<b>2020</b> <b>£</b>	<b>2019</b> <b>£</b>
Bank interest	<b>775</b>	<b>6,126</b>

**5. RAISING FUNDS**

	<b>2020</b> <b>£</b>	<b>2019</b> <b>£</b>
Staff costs	114,642	93,883
Fundraising and publicity	56,459	46,706
Events and promotions	89,631	17,115
Cost of merchandise sales	6,658	6,127
	<b>267,390</b>	<b>163,831</b>



## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2020 - continued

#### 6. CHARITABLE ACTIVITIES COSTS

##### Provision of support

	2020 £	2019 £
Staff costs	242,403	223,724
Information and awareness raising	18,218	28,385
Shared experience network	14,163	9,484
Outreach Service	57,256	38,354
Information, support and social events	-	71,633
Welfare and equipment grants	15,346	14,288
	<b><u>347,386</u></b>	<b><u>385,868</u></b>

##### Pursuit of knowledge

	2020 £	2019 £
Staff costs	73,345	64,823
Medical research grants	31,084	41,302
Other research activities	19,510	17,941
	<b><u>123,939</u></b>	<b><u>124,066</u></b>

#### 7. GOVERNANCE COSTS

	2020 £	2019 £
Staff costs	72,467	46,192
Professional fees and bank charges	17,107	20,333
Other costs	15,421	21,715
Committee expenses	4,107	4,016
	<b><u>109,102</u></b>	<b><u>92,256</u></b>

#### 8. NET INCOME / (EXPENDITURE)

	2020 £	2019 £
Depreciation – owned assets	5,830	11,315
<b>Fees payable to auditor for:</b>		
-audit	1,500	1,500
-other services	2,950	2,950

**Spinal Muscular Atrophy UK**  
**Notes to the Financial Statements for the Year Ended 31 March 2020 - continued**

**9. TRUSTEES' REMUNERATION AND BENEFITS**

There were no Trustees' remuneration or other benefits for the year ended 31 March 2020 nor for the year ended 31 March 2019.

**Trustees' expenses**

Expenses totalling £3,338 (2019: £1,386) were reimbursed to 2 (2019: 2) Trustees in respect of travel and subsistence for committee meetings and fundraising activities during the year.

Payment in respect of Trustee indemnity insurance amounted to £912 (2019: £829)

**10. STAFF COSTS**

	<b>2020</b> <b>£</b>	<b>2019</b> <b>£</b>
Wages and salaries	362,105	360,559
Social security costs	32,485	33,904
Pension	18,345	15,174
	<b><u>412,935</u></b>	<b><u>409,637</u></b>

The average monthly number of employees (Full Time Equivalents (FTE)) during the year was as follows:

<b>Staff</b>	<b>2020</b>	<b>2019</b>
Management and administration	1.3	2
Direct charitable expenditure	6.2	7
Fundraising and publicity	3.1	3
	<b><u>10.6</u></b>	<b><u>12</u></b>

We also engaged contractors in 2020 to assist us with our management and administration 1.1 FTE and 0.6 in fundraising and publicity.

No employees or contractors received emoluments in excess of £60,000 (2019: None)

# Spinal Muscular Atrophy UK

## Notes to the Financial Statements for the Year Ended 31 March 2020 - continued

### 11. TANGIBLE FIXED ASSETS

	Improvements to property £	Office equipment £	Database £	Computer equipment £	Totals £
<b>COST</b>					
At 1 April 2019	19,611	4,607	31,312	19,982	75,512
Additions	-	-	-	1,105	1,105
At 31 March 2020	<u>19,611</u>	<u>4,607</u>	<u>31,312</u>	<u>21,087</u>	<u>76,617</u>
<b>DEPRECIATION</b>					
At 1 April 2019	19,611	3,988	29,076	11,999	64,674
Charge for year	-	229	2,236	3,365	5,830
At 31 March 2020	<u>19,611</u>	<u>4,217</u>	<u>31,312</u>	<u>15,364</u>	<u>70,504</u>
<b>NET BOOK VALUE</b>					
At 31 March 2020	-	<u>390</u>	-	<u>5,723</u>	<u>6,113</u>
At 31 March 2019	-	<u>619</u>	<u>2,236</u>	<u>7,983</u>	<u>10,838</u>

### 12. STOCKS

	2020 £	2019 £
Stocks held for re-sale	<u>7,835</u>	<u>2,570</u>

### 13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Other debtors	-	1,750
Prepayments and accrued income	42,191	46,494
	<u>42,191</u>	<u>48,244</u>

### 14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Social security and other taxes	10,956	13,414
Other creditors	13,044	11,426
Accrued expenses	13,762	13,683
	<u>37,762</u>	<u>38,523</u>

### 15. LEASING AGREEMENTS

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

	2020 £	2019 £
Within one year	28,830	22,347
Between one and five years	78,901	16,497
	<u>107,731</u>	<u>38,844</u>

## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2020 - continued

#### 16. MOVEMENT IN FUNDS

##### Statement of funds

	Balance b/f at 1.4.19 £	Incoming Resources £	Resources Expended £	Funds Transfer	Balance c/f at 31.3.20 £
<b>Unrestricted funds</b>					
General funds	<u>212,768</u>	<u>751,567</u>	<u>(646,870)</u>	<u>(18,766)</u>	<u>298,699</u>
<b>Restricted funds</b>					
Support into the 2020s – Lotteries Reaching Communities	944	124,303	(134,013)	8,766	-
Support into the 2020s – Other Grants	4,218	35,000	(39,218)	-	-
Toy Packs & Car Seats	3,000	-	(1,273)	-	1,727
Research - Robert Luff Foundation	-	10,000	(8,750)	-	1,250
Flexible Response Grants	7,000	5,000	(8,330)	-	3,670
Living with SMA and the Standards of Care	7,600	-	(8,740)	10,000	8,860
Equipment Grant	500	-	(500)	-	-
Northern Ireland Events	1,778	-	(123)	-	1,655
<b>Total Restricted Funds</b>	<u>25,040</u>	<u>174,303</u>	<u>(200,947)</u>	<u>18,766</u>	<u>17,162</u>
<b>TOTAL FUNDS</b>	<u><b>237,808</b></u>	<u><b>925,870</b></u>	<u><b>(847,817)</b></u>	-	<u><b>315,861</b></u>

##### Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
<b>Fund balances at 31 March 2020 are represented by:</b>			
Tangible fixed assets	6,113	-	6,113
Stock	7,835	-	7,835
Debtors	42,191	-	42,191
Bank and cash	280,322	17,162	297,484
Current liabilities	(37,762)	-	(37,762)
<b>Total net assets</b>	<u><b>298,699</b></u>	<u><b>17,162</b></u>	<u><b>315,861</b></u>

## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2020 - continued

## 16. MOVEMENT IN FUNDS - continued

### Support into the 2020s

This includes the services and workstreams described in the section, 'Achievements and Performance': information production, outreach, sharing experiences (networks and events) and speaking up for SMA (advocacy – in particular for access to drug treatments).

It is funded by:

- **Lotteries Reaching Communities** - This is a new 3-year grant 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 & Car Seats

Our multisensory toy packs are available free of charge to families in the UK for children newly diagnosed with SMA or SMARD. 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. We also fund car seats for infants.

### Research Robert Luff Foundation

This grant contributed to the coordination costs needed to maintain the UK SMA Research Consortium. Since 2016, this has received £1,327,708 from SMA UK. It consists of 6 world-class research teams based in Oxford, Edinburgh, Sheffield and London. The teams work collaboratively across 4 main areas:

- Exploring the ways in which SMA affects different organs / systems within the body and which might be targets for treatments.
- Looking at what treatments could be beneficial if used in combination with current SMN-boosting drugs like nusinersen (Spinraza™).
- Developing models to test out potential treatments.
- Looking at new methods of drug delivery including in the womb.

### Flexible Response Grants

This fund enables grants to be made to individuals and families affected by SMA. It provides a swift response to an urgent need when no other funding source is available. Grants are typically small.

### Living With SMA and the Standards of Care

This project enabled us to review, re-work and integrate all the information we had in our 'Route Maps for SMA' to make it more accessible and user-friendly in a new website area called 'Living With SMA' divided into sections for parents of children, teenagers and adults. Additionally, following the revision of the International Standards of Care for SMA (SoC) published in November 2017, our staff worked extensively with an international group to produce the family-friendly version which was published in June 2019. Our original plans to run webinars with clinical experts changed to developing a new section of Living With SMA. This covers the SoC and health-related topics and will incorporate short clips and recordings of clinical experts talking about aspects of care.

**Equipment Grant**

This fund covers final outstanding equipment grants.

**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 have fun.

**17. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 31 March 2020.

## Spinal Muscular Atrophy UK

### DETAILED STATEMENT OF FINANCIAL ACTIVITIES for the year ended 31 March 2020

	2020 £	2019 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations and gifts	795,531	547,863
Legacies	-	200
SMA Trust fund donation	-	176,125
Lotteries – Reaching Communities	124,302	66,118
	<b>919,833</b>	<b>790,306</b>
<b>Other trading activities</b>		
Merchandise sales	5,262	4,208
Rental income	-	178
	<u>5,262</u>	<u>4,386</u>
<b>Investment income</b>		
Bank interest	775	6,126
<b>Total incoming resources</b>	<b>925,870</b>	<b>800,818</b>
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Staff costs	114,642	93,883
Fundraising and publicity	56,459	46,706
Events and promotions	89,631	17,115
Cost of merchandise sales	6,658	6,127
	<b>267,390</b>	<b>163,831</b>
<b>Charitable activities</b>		
Staff costs	315,748	288,547
Medical research grants	31,083	41,302
Other research activities	19,511	17,941
Information and awareness raising	18,217	28,385
Shared experiences network	14,163	9,484
Outreach Service	57,258	38,354
Information support and social events	-	71,632
Welfare, equipment grants and toy packs	15,345	14,289
	<b>471,325</b>	<b>509,934</b>
<b>Governance Costs</b>		
<b>Management</b>		
Staff costs	72,467	46,192
Professional fees and bank charges	17,107	20,333
Other costs	15,421	21,714
Committee expenses	4,107	4,016
	<u>109,102</u>	<u>92,255</u>
<b>Total resources expended</b>	<b>847,817</b>	<b>766,020</b>
<b>Net income</b>	<b>78,053</b>	<b>34,798</b>

This page does not form part of the statutory financial statements



**Spinal Muscular Atrophy UK**  
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CV37 9NR

**Phone:** 01789 267520

- Mon – Thurs (9.00am – 3.30pm)
- Friday (9.00am – 1.00pm)
- Closed on public holidays.

**Email:** [office@smauk.org.uk](mailto:office@smauk.org.uk)  
**[www.smauk.org.uk](http://www.smauk.org.uk)**



**Help for today, hope for tomorrow**

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