

# Annual Report & Financial Statements

For the year ending 31<sup>st</sup> March 2022



Help for today, hope for tomorrow



## **Welcome to our Annual Report and Financial Statements**

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## Letter from the Chair

2021 was a transformational year for the SMA Community – a year of highs and lows, anxiety and excitement. The impact of Covid and the need for isolation for many was wearing heavy. But, at the same time, there was the very welcome news early in the year that the gene therapy drug Zolgensma™ was approved for NHS use in the UK. Another ‘win’ was the news later in the year that Evrysdi™ (risdiplam) would also be funded by the NHS. We are delighted as this means there are now three treatments for SMA, with varying eligibility criteria.

We have been providing information and updates about all these developments to assist people so that they can have informed conversations with their clinicians. We have also continued to work closely with our NHS colleagues with the aim of ensuring that treatments reach everyone for whom they are clinically appropriate.

Whilst we are of course excited by the potential of these new treatments, it is widely recognised that all treatments are more effective the earlier they are given. This year, as a key member of the UK SMA Newborn Screening Alliance, we will be working even harder for SMA to be included as part of the routine bloodspot testing of all newborns.

Care, as well as access to treatments, has taken centre-stage for many this year as the NHS and Social Services nationally have struggled to juggle priorities. We have increasingly been able to lend our voice to that of others to advocate on these wider issues. As part of this, we have worked alongside Community members who have shared their experiences of, for example, the shortage of Personal Assistants (PAs), as well as other topics of interest in our growing podcast series.

Our dedicated Outreach & Support Team have worked hard to meet the 30% increase in demand in services in 2021 compared to 2020. At the same time, our income was still impacted significantly by Covid but, thanks to our loyal fundraisers

who were again able to take part in, or organise, baking, running, walking, cycling, and more, to support the charity, this gradually picked up over the summer. A special thanks as well to our long-term funding partners such as the National Lottery Community Fund and the pharma sector.

As we look forwards, we know SMA UK has a key part to play in supporting our Community to be more connected, better informed and to build awareness about SMA in the general population. We will share these messages via a range of channels, upgrading our website, and extending our Podcast and Webinar series which shares experiences, stories, life-hacks and challenges, as well as updates from health professionals. At the time of writing, the return to face-to-face events is also happily underway. These are being held regionally throughout the UK in June and July.

Our membership of SMA Europe, which brings together 23 countries who all share the agenda of ‘creating a better world for all those with SMA’, further extends our reach. In the UK we are also proud to work in partnerships with like-minded organisations such as MDUK and TreatSMA, amongst others.

Internally, our organisation has continued to evolve and develop. Remote working has allowed us to recruit beyond our traditional office base in the Midlands, opening up opportunities to build our team as well as reaching families and adults in ways we had never imagined possible.

Finally, I would like to thank our CEO, Angela Smith-Morgan, her amazing team, and our wonderful volunteers including all the Trustees, who have worked so hard to help SMA UK deliver for our Community.



**Mark Dearlove, July 2022**

## Trustees' Strategic Report

Spinal Muscular Atrophy (SMA) is a rare, genetic, neuromuscular condition causing progressive muscle wasting (atrophy) and weakness leading to loss of movement. This may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. There are different forms of SMA and a wide spectrum of how severely children and adults are affected.

Based on 2017 global studies of the numbers of people born with and living with SMA, it has been thought that there are between 670 – 1340 children, young people and adults, who have SMA, living in the UK. This was before the new drug treatments and the impact this has had, in particular on the survival of children who have the most severe Type, SMA Type 1. We would therefore expect the population to be slowly increasing as there are now some 65 – 70 babies born each year with some form of SMA. Approximately 60% will be diagnosed with SMA Type 1.



## Our Charity

Spinal Muscular Atrophy UK was founded in 1985 as the Jennifer Trust for SMA which merged with the SMA Trust in 2018 to become the charity it is today.

## 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.

## 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 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; opportunities to have contact with others affected by the condition.
- Wider advocacy for services and access to care and drug treatments.
- 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
- New drug treatments and clinical trials
- Equipment and adaptations

We are **advocates** on behalf of the SMA Community to authorities that regulate access to drug treatments, care and services. We **support developments** that improve and monitor access to services and drug treatments.

We work with other charities, with health, education and social care professionals, and with national and international charities and organisations to **campaign** on issues that matter to people affected by SMA.



### 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.

Since 1986, we have raised and donated over £5 million in support of research. Our strong connections and collaborations with other UK and international SMA charities and groups, clinicians, researchers and the pharmaceutical industry, ensure best use of any funds we allocate to research-related initiatives.

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

## Achievements & Performance

### Issues faced by the SMA Community

We estimate that there are now as many as 150 children in England who have SMA Type 1 and who have been treated since 2018. They need regular physiotherapy, speech and language therapy, dietary advice and specialist equipment, and family homes need significant adaptations; but these services haven't grown or kept pace with the need. Similarly, many nurseries and schools do not have the experience, and sadly not all show a willingness, to provide the education and facilities needed by these children who are very bright and eager to learn.

Few adults have access to regular physiotherapy despite it being widely agreed that this is vital - as are assessments and advice from other clinical specialists, for example dieticians.

It is well-documented<sup>1</sup> that life costs more for disabled people and their families than for others anyway. On top of this, for many, the combination of Covid, Brexit and insufficient levels of funding for care packages, has presented huge challenges with recruiting and retaining carers / personal assistants. Added to this we now have a potentially huge increase in the cost of living, particularly the cost of energy, which impacts disproportionately on children, young people and adults who need night-time ventilation, a cough assist machine, powered wheelchairs – to name just a few essentials in their lives. Health, education and funding of support, are simply not keeping pace with the growing needs of the current SMA Community, but without these services the full benefits of treatment cannot be realised.

And though this year saw yet another huge breakthrough with the NHS adding funding of risdiplam as a possible treatment, access for many adults has been slow and we are still not home and dry in terms of permanent access for all.

### What does the Community want from us?

In September 2021, our survey to the SMA Community asked, 'What do you want from SMA UK?'. We had 145 responses which, given how 'surveyed out' our Community is, was an excellent response rate. Asked what we should provide:

**More than 90%** said:



**Information** about SMA, care and services, access to treatments and research and treatment developments.



**Outreach and support** following diagnosis and at challenging times.

**More than 80%** said:



**Podcasts, videos, people's stories** and, when possible, **face-to-face events**.



**Advocacy** for better, faster access to **treatments** and **newborn screening for SMA**, and access to **better health & social care**.

<sup>1</sup> [www.scope.org.uk/campaigns/extra-costs/](http://www.scope.org.uk/campaigns/extra-costs/)

## What did we do about all this?

Our 2021 Support Services Team (Liz, Jackie, Jo, Maggie, Claire, Libby, Dermot & Michele) worked to respond to all these Community priorities.



### Information

We met the Community’s request for information by providing relevant, up to date, evidence-based, accurate information relating to SMA – about the condition and its management, clinical trial results and the new drug treatments. These last two topics are covered by our trusty Research Correspondents, James and Vanessa.



We also couldn’t do this without the support of the clinical experts who review our information, and without feedback from our target audiences. Our thanks to them all.



*“I find your leaflets family-friendly and gentle in the information given, yet clear and concise - they make a huge difference when families are given the diagnosis.”* **Neuromuscular Care Advisor**

Our website continued to be popular:

### Website Visitors

2019	2020	2021
67,795	84,272	101,978

### Top Unique Page Views 2021

Page	Unique Views
Information	10,030
Support	7,389
Treatment & Research	7,366
Recent Diagnosis SMA Type 1	6,890
Zolgensma	5,961
Risdiplam	5,736
Nusinersen	5,571

We were audited by, and accredited to, the Patient Information Forum which replaced the Information Standard.



### Living With SMA Website Visitors

2020	2021
2,800	4,600

Divided into three main sections for parents of children, teenagers and adults, this website section builds on knowledge and advice from the SMA Community and SMA UK’s Support Team. It covers a whole host of topics including health & wellbeing, equipment, homes, education, work, transport, leisure, and financial, emotional and social support.

We try to extend our reach into the SMA Community by using a number of social media platforms. Our monthly E-news bulletin yet again saw an increase in people on the mailing list to almost 3,300, with an open-rate consistently well above the

sector norm of 21%. These mailings kept the Community informed about access to treatment developments, consultations, surveys, fundraising activities, and other information and news.

We run monthly reports to collect statistics on our social media:

December	2020	2021
Facebook likes	4,865	5,263
Twitter followers	2,110	2,462
Instagram followers	1,537	1,958

We also started putting more content out on LinkedIn and monitoring the stats on this, increasing our followers to 378 by December 2021.

With so many different ways of being in touch, and not always knowing who we're reaching, it's difficult to know exactly how many people we're in touch with have SMA and are in the UK. Our best estimate, based on our mailing list, is that we're in contact with some 780 households where there is a parent of a child / young person who has SMA or an adult who has SMA (2019: 600). Similarly, we're in contact with more than 360 families bereaved by SMA.

### Outreach and Support

This service was also high on the Community list as one SMA UK should provide. Though we were again unable to make home visits for most of the year due to Covid, we still provided individual support across the UK by phone, email and Zoom call to parents of children who have SMA and to young people and adults who have SMA, and their families. Everyone's circumstances, requests and needs were different, with more and more people facing the complex and challenging times outlined earlier in this summary.

*"We really appreciate all the help and support you give us; without it we wouldn't be at this point we are now. Thank you so much."* **Parent**

Affected children, young people or adults	Numbers 2020	Numbers 2021
New to SMA UK	83	113
Returned to SMA UK	124	156
<b>Total</b>	<b>207</b>	<b>269</b>

As part of this service, we offer families with an infant up to 12 months of age a free multisensory toypack. Though every toy pack we send out means another family is struggling with a devastating diagnosis, we know how much fun and joy they can bring. This year, we sent out 33.



*"Thank you so much! The toys are wonderful."* **Parent**

For some queries, we were also able to draw on the tips, ideas and experiences of our generous volunteers who form our Community Questions Network. That's 75 adults who have SMA, parents, grandparents and others.

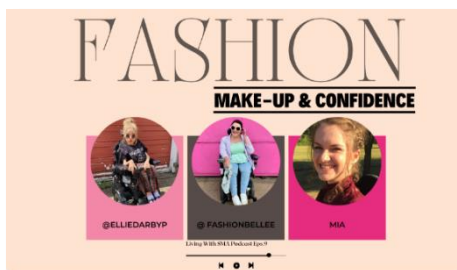
We wished Maggie, who had been an Outreach Worker with us since 2006, a very happy retirement. We and many in the Community will greatly miss her. Looking forward, though, we are very pleased that Rebecca joins the Outreach Team in July 2022.





Though we continued to focus on the UK, we always replied to overseas enquiries, many from families desperately seeking treatment. We did our best to link people in to support networks and give relevant information.

**Podcasts, videos, people’s stories and, when possible, face-to-face events**



Our response to this priority saw the release of podcasts and videos on an ever-increasing range of topics - made by and with the SMA Community. Recent examples were: PAs Aren’t Just For Care; Health Screening; Periods; Employment & Blogging; Hitting Your Forties.

It wasn’t possible to plan any face-to-face events given the uncertainty over Covid and that many people were still self-isolating. We did, though, offer a number of virtual events including a 12-week Mindfulness Course. We also continued to offer people the chance to connect up with each other to share experiences, tips and ideas via our community networks.

Network	No. Of members
<a href="#">Adults</a>	89
<a href="#">Young Adults</a>	24

Looking forward to later in 2022, we are venturing into face-to-face events with 6 summer Picnic In The Parks planned in different regions across the UK.



We are also really pleased to have Luis joining the team in May 2022 to help us grow the Living With SMA podcast series.

**Advocacy for treatments and access to better health and social care**

We responded to this Community priority again when we joined with the other patient groups and clinicians advocating strongly both in England and Scotland. Access to Zolgensma™ for some children who have SMA Type 1 was announced in both countries in March 2022. Positive decisions for access to risdiplam for those who have SMA Type 1, 2 or 3 were announced in December 2021 and February 2022. The other devolved countries also followed these leads.

We continue to be members of the national groups in England that monitor the roll-out of the managed access programmes for Spinraza™ (nusinersen) and Evrysdi™ (risdiplam) and will be involved in the review of these in due course.



Advocacy for treatment has been a huge amount of work and though we have advocated on other issues, when possible, our capacity to do so has been limited. In January 2022, we were therefore delighted to welcome Portia to the team as Advocacy Lead.

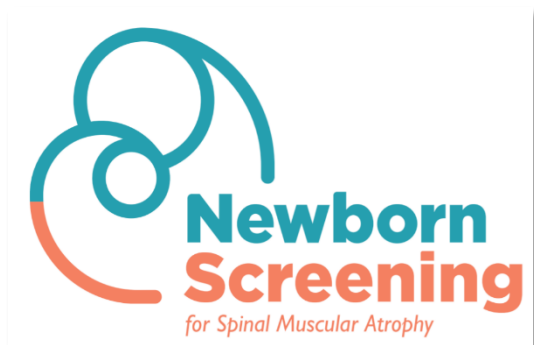
**We hope our efforts to respond to the Community’s priorities have, in some small way, helped to ease the enormous challenges people face today, and that others might echo this parent’s reflection:**

*“What my family most value your service for is as support (being knowledgeable in all things relating to SMA whenever we get in touch to ask about it) and putting us in touch with other families who can offer emotional support, and advocating for access to relevant equipment adaptations etc.” Parent*

## Advocacy for Newborn Screening for SMA

The SMA Community has witnessed phenomenal developments over the last few years, with the three ground-breaking treatments that are potentially life-changing for children, young people and adults. Evidence does, though, clearly show that the earlier the treatment, the better the potential outcome, with the best possible outcome if the treatment is given before a baby shows any symptoms. Carried out within a few days of birth, the current NHS newborn blood spot (NBS) screening programme supports the early identification, referral and treatment of babies with nine rare but serious conditions. SMA is not currently one of them so we will be working on the Community's priority to see SMA added to this programme.

To this end, we are members of the UK SMA Newborn Screening Alliance chaired by Professor Laurent Servais, Professor of Paediatric Neuromuscular Diseases at the MDUK Oxford Neuromuscular Centre. The Alliance includes leading SMA experts in the clinical and academic community and patient organisations. SMA UK and Muscular Dystrophy UK form the Secretariat and have worked with Laurent to recruit Project Manager, Alice Fabre. You will be hearing much more from the Alliance in 2022 / 23.



Our advocacy work continued to be enhanced by our membership of many Alliances within the UK and also our membership of SMA Europe. With a mission of “*working to bring effective treatments and optimal care to everyone living with SMA*”, it brings together 24 patient organisations from 23 countries. They support each other to advocate and campaign at national level, while also engaging and influencing stakeholders and

decisions at European level through SMA Europe itself.



## Ukraine Appeal



In March 2022 we joined forces with SMA Europe, TreatSMA and other UK SMA patient groups to provide our SMA Community with a way to help fund and support the Ukrainian SMA families and individuals so terribly affected by the devastating conflict. At the time of writing this report, £3864.66 had been donated and transferred to the SMA Poland charity which is working 24/7 with families in Ukraine to organise emergency transportation and accommodation.

## Research Grants

At the end of March, we were delighted to announce with MDUK our joint funding of a four-year PhD studentship in SMA research. This was awarded to Dr Lyndsay Murray of the University of Edinburgh. Dr Murray will be studying an interesting biological mechanism seen in SMA called motor unit enlargement, a process that occurs in the muscles of people with SMA.

We also fulfilled our commitment to contribute funding to SMA Europe's 'call' which will select and fund new research projects.

## Fundraising and Our Supporters

We are humbled by the incredible support our donors and fundraisers have given to SMA UK. We could not do what we do without you. Thank you.

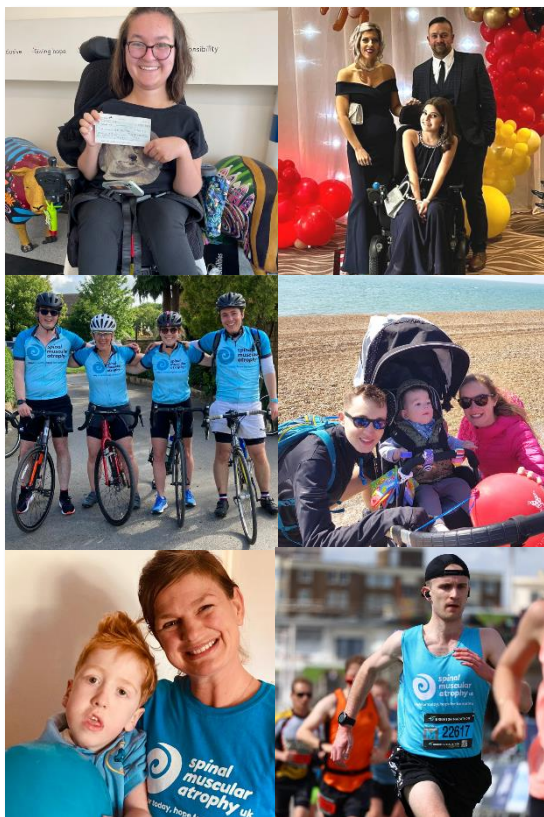
### Community Fundraising

We were delighted to be able to see a return to some in-person fundraising events during this past year, although we were still feeling the effects of the pandemic with significantly fewer events taking place than in previous years.

Our virtual fundraiser, Marathon in May, was well supported once again, along with our Christmas Jumper Day and annual festive matched funding campaign, The Big Give Christmas Challenge.

We were supported by people taking part in a huge range of events – from Chillswims to Skydives – and were proud to have seven runners in the London Marathon who all did amazingly with their fundraising.

We would like to take this opportunity to thank everyone who made a donation, including our regular givers and those who fundraised in memory of a loved one or left a legacy.



## Trust and Corporate Fundraising

We are very grateful to the many Trusts, corporate donors, and pharmaceutical companies, who have generously supported our work again this year. We continued to benefit from the support of the National Lottery Community Fund which also enabled us to attract 'matched funding' from other Trusts and Foundations.

Every donation really does count, and we are so grateful for the continued support of our wonderful Community.



## Our Fundraising Team

A thank you also to Caroline who led the Fundraising Team, and Debbie who managed our applications to Trusts. Rebecca and Yvonne have now been joined by Lucy and Stacey. The team looks forward to continuing to work to raise funds so that SMA UK can continue to respond to what the Community wants from the charity.



## Report of the Trustees for the year ended 31 March 2022

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 2022. 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.

### 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

#### Achievements and Performance

See pages 6 - 10.

### Future Plans

We will continue to: advocate for access to the new drug treatments, representing the views of the SMA Community to regulatory authorities and pharmaceutical companies; monitor the roll-out of NHS programmes and pharmaceutical initiatives supporting individuals seeking access. We will continue to provide and further develop our information, outreach and support services and opportunities for people in the SMA Community to connect with each other. Our fundraising efforts will need to achieve income levels that will enable us to achieve our goals. We will continue to adapt our working practices to ensure they are safe for both the SMA Community and our staff and Trustees.

### Financial Review

#### Financial Position

See page 15 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 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 changed circumstances of the Covid-19 pandemic, Trustees have temporarily 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.

### **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 management experience of the 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 four times a year, and the meetings have been held remotely since the COVID pandemic. Going forward the aim is to have a balance of remote and face-to-face meetings.

### **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**

<b>Registered Company number</b> 05137534 (England and Wales)	<b>Registered Charity number</b> 1106815
<b>Registered office</b> – Unit 9 Shottery Brook Office Park, Timothy’s Bridge Road, Stratford-upon-Avon, CV37 9NR	
<b>Trustees</b>  Dr A M Childs, M P Collins, M T Dearlove, K Y Edwards, J M Fiorentini, C M Gray, K M Jackson, C S B Knight, S Madipalli, T J Mildon, B M O Morris, Dr R Quinlivan, T J D Sheffield, Dr A M E Smith, D J Waltier, L E J West.	
<b>Company Secretary</b>  A Smith-Morgan	
<b>Auditors</b>  Cooper Adams Ltd, Chartered Accountants and Statutory Auditors, 12 Payton Street, Stratford-upon-Avon, Warwickshire CV37 6UA	
<b>Chair</b>  M T Dearlove	<b>Patrons</b>  Professor V Dubowitz

Report of the Trustees, incorporating a strategic report, approved by order of the board of Trustees, as the company directors, on ..... **4<sup>th</sup> August 2022** ..... and signed on the Board's behalf by:



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

## Treasurer's Report

This has been a more positive year financially for SMA UK as we have been able to return to a more normal level of activity. Although income is not back to pre-pandemic levels, the charity has benefited from a more stable funding environment enabling the charity to begin to return to previous levels of engagement with the Community.

Income for the year was £839k, an increase of nearly 16% on the prior year. This was driven primarily by an increase in funds from Trustee and Community fundraising events as in-person fundraising has become possible again during the year, with tremendous efforts from the fundraising team and Trustees. The charity has benefited from continued Lottery and Trust funding, but pharma support has decreased on prior year. The ending of the Government furlough and Covid support schemes has resulted in a reduction of £54k in funding which was being utilised to mitigate staff costs.

The total pharmaceutical funding received during the year was £45,250 which was 5% of total income as compared to 15.5% in the prior year. Specific donations received in 2021/22 were £38,725 from Roche and £6,500 from Biogen. The support from pharmaceuticals varies depending on their priorities in any one year and we expect increased support in 2022/3 for the UK SMA Newborn Screening Alliance, of which we are a key member. 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 compromise our charitable objectives or independence.

SMA UK's spending is broadly divided between information provision, support and research-related activities - 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. The charity cut back on expenditure significantly during the height of the pandemic period last year and took a number of steps to reduce costs. This year it has been able to increase its activities in support of the Community and has been

pleased to provide research grants (which had been curtailed during the pandemic) via its partnerships with SMA Europe and MDUK. Fundraising expenditure in support of events was increased by £16k with pleasing results in terms of increased fundraising.

The total result of these changes has meant an increase in expenditure in the year of £140k, or 24%. 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 63p to 68p as resources were focused on provision of support to the SMA Community and research-related initiatives.

Our net income for 2021/22 was a surplus of £124k compared to £149k in the prior year. This result is a strong one given the changes in pharmaceutical and government support and the positive impact that the team have been able to have. 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 2022/3 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 £591k and the board will continue to monitor activities and reserves very carefully. I would like to thank all the SMA UK team for their hard work, resilience and flexibility during the year.



**Katharine Jackson,  
July 2022**

# SMA UK REPORT OF THE INDEPENDENT AUDITORS TO THE MEMBERS OF SPINAL MUSCULAR ATROPHY UK

## Opinion

We have audited the financial statements of Spinal Muscular Atrophy UK (the 'charitable company') for the year ended 31 March 2022 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 2022 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

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 company's 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.



## **SMA UK REPORT OF THE INDEPENDENT AUDITORS TO THE MEMBERS OF SPINAL MUSCULAR ATROPHY UK**

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.

### **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.

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 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: 4<sup>th</sup> August 2022

**Spinal Muscular Atrophy UK**  
**STATEMENT OF FINANCIAL ACTIVITIES for the Year Ended 31 March 2022**

	Notes	Unrestricted Funds £	Restricted Funds £	2022 Total Funds £	2021 Total Funds £
<b>INCOME &amp; ENDOWMENTS FROM</b>					
Donations & legacies	2	579,516	255,080	834,596	720,690
Other trading activities	3	4,694	-	4,694	3,740
Investment income	4	130	-	130	261
<b>Total</b>		<u>584,340</u>	<u>255,080</u>	<u>839,420</u>	<u>724,691</u>
<b>EXPENDITURE ON</b>					
Raising funds	5	161,871	-	161,871	145,613
<b>Charitable activities</b>	6				
Provision of support		153,498	226,022	379,520	308,139
Governance costs		68,228	-	68,228	67,455
Research-related activity*		95,847	10,000	105,847	54,135
<b>Total</b>		<u>479,444</u>	<u>236,022</u>	<u>715,466</u>	<u>575,342</u>
<b>NET INCOME</b>		104,896	19,058	123,954	149,349
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		443,941	21,269	465,210	315,861
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u>548,837</u>	<u>40,327</u>	<u>589,164</u>	<u>465,210</u>

\*In last year's accounts, this was referred to as 'Pursuit of Knowledge'.

The notes form part of these financial statements

**Spinal Muscular Atrophy UK**  
**Statement of Financial Position at 31 March 2022**

	Notes	Unrestricted Funds £	Restricted Funds £	2022 Total Funds £	2021 Total Funds £
<b>FIXED ASSETS</b>					
Tangible assets	11	8,116	-	8,116	4,146
<b>CURRENT ASSETS</b>					
Stocks	12	6,285	-	6,285	6,256
Debtors	13	11,951	3,288	15,239	8,639
Cash at bank and in hand		551,527	39,677	591,204	468,926
		<u>569,763</u>	<u>42,965</u>	<u>612,728</u>	483,821
<b>CREDITORS</b>					
Amounts falling due within one year	14	(29,042)	(2,638)	(31,680)	(22,757)
<b>NET CURRENT ASSETS</b>		<u>540,721</u>	<u>40,327</u>	<u>581,048</u>	<u>461,064</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		548,837	40,327	589,164	465,210
<b>NET ASSETS</b>		<b><u>548,837</u></b>	<b><u>40,327</u></b>	<b><u>589,164</u></b>	<b><u>465,210</u></b>
<b>FUNDS</b>					
Unrestricted funds: General fund	16			548,837	443,941
Restricted funds: Various – see note 16				40,327	21,269
<b>TOTAL FUNDS</b>				<b><u>589,164</u></b>	<b><u>465,210</u></b>

The financial statements were approved by the Board of Trustees and authorised for issue on

**4<sup>th</sup> August 2022** 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 2022**

	Notes	2022 £	2021 £
<b>Cash flows from operating activities:</b>			
Cash generated from operations	1	130,371	172,138
Net cash provided by operating activities		130,371	172,138
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		(8,223)	(2,574)
Sale of tangible fixed assets		-	1,617
Dividends received		130	261
Net cash used in investing activities		(8,093)	(696)
<b>Change in cash and cash equivalents in the reporting period</b>		<b>122,278</b>	<b>171,442</b>
<b>Cash and cash equivalents at the beginning of the reporting period</b>		<b>468,926</b>	<b>297,484</b>
<b>Cash and cash equivalents at the end of the reporting period</b>		<b><u>591,204</u></b>	<b><u>468,926</u></b>

**Notes to the Statement of Cash Flows**  
**For the Year Ended 31 March 2022**

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

	2022 £	2021 £
<b>Net income for the reporting period (as per the Statement of Financial Activities)</b>	123,954	149,349
<b>Adjustments for:</b>		
Depreciation charges	4,253	2,924
Dividends received	(130)	(261)
(Increase)/decrease in stocks	(29)	1,579
(Increase)/decrease in debtors	(6,600)	33,552
Increase/(decrease) in creditors	8,923	(15,005)
<b>Net cash provided by operations</b>	<b><u>130,371</u></b>	<b><u>172,138</u></b>

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

	At 1.4.21 £	Cash flow £	At 31.3.22 £
<b>Net Cash</b>	468,926	122,278	591,204
Cash at bank and in hand	468,926	122,278	591,204
Total	<u>468,926</u>	<u>122,278</u>	<u>591,204</u>

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:

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

### 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 2022 - continued

#### 2. DONATIONS AND LEGACIES

	2022 £	2021 £
Donations and gifts	680,272	539,606
Legacies	25,000	-
Government Grants Covid-19	-	54,295
The National Lottery Community Fund	129,324	126,789
	<b>834,596</b>	<b>720,690</b>

#### 3. OTHER TRADING ACTIVITIES

	2022 £	2021 £
Merchandise sales	<b>4,694</b>	<b>3,740</b>

#### 4. INVESTMENT INCOME

	2022 £	2021 £
Bank interest	<b>130</b>	<b>261</b>

#### 5. RAISING FUNDS

##### Raising donations and legacies

	2022 £	2021 £
Staff costs and other expenses	94,642	106,829
Fundraising and publicity	25,817	24,891
Events and promotions	38,702	11,939
Cost of merchandise sales	2,710	1,954
	<b>161,871</b>	<b>145,613</b>

**Spinal Muscular Atrophy UK**  
**Notes to the Financial Statements for the Year Ended 31 March 2022 - continued**

**6. CHARITABLE ACTIVITIES COSTS**

**Provision of support**

	<b>2022 £</b>	<b>2021 £</b>
Staff costs and other expenses	227,712	239,039
Information and awareness raising	7,465	5,941
Shared experiences network	27,048	13,009
Outreach Service	37,923	44,957
Welfare and equipment grants	29,372	5,193
	<b><u>379,520</u></b>	<b><u>308,139</u></b>

**Research-Related Activity\***

	<b>2022 £</b>	<b>2021 £</b>
Staff costs and other expenses	64,423	32,546
Research-related grants	35,072	16,251
Other research activities	6,352	5,338
	<b><u>105,847</u></b>	<b><u>54,135</u></b>

**7. ADMINISTRATION & MANAGEMENT COSTS\*\***

	<b>2022 £</b>	<b>2021 £</b>
Staff costs and other expenses	48,301	42,103
Professional fees and bank charges	8,939	6,407
Other costs	10,988	13,589
Committee expenses	-	5,356
	<b><u>68,228</u></b>	<b><u>67,455</u></b>

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

	<b>2022 £</b>	<b>2021 £</b>
Depreciation – owned assets	4,253	2,924
<b>Fees payable to auditor for:</b>		
- audit	1,500	1,500
- other services	3,265	2,995

\*In last year's accounts, this was referred to as 'Pursuit of Knowledge'.

\*\*In last year's accounts, these were referred to as Support Costs



**Spinal Muscular Atrophy UK**  
**Notes to the Financial Statements for the Year Ended 31 March 2022 - continued**

**9. TRUSTEES' REMUNERATION AND BENEFITS**

There were no Trustees' remuneration or other benefits for the year ended 31 March 2022 nor for the year ended 31 March 2021.

**Trustees' expenses**

Expenses totalling £nil (2021: £nil) were reimbursed to nil (2021: nil) 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 £398 (2021: £973)

**10. ALL STAFF COSTS**

	<b>2022</b> <b>£</b>	<b>2021</b> <b>£</b>
Wages and salaries	391,466	344,518
Social security costs	34,664	29,811
Pension	17,288	16,108
	<b><u>443,418</u></b>	<b><u>390,437</u></b>

The average monthly number of employees during the year was as follows:

	<b>2022</b>	<b>2021</b>
Management and administration	1	1
Direct charitable expenditure	8	8
Fundraising and publicity	3	3
	<b><u>12</u></b>	<b><u>12</u></b>

We also engaged 1.2 FTE contractors in 2021 to assist us with our management and administration.

No employees received emoluments in excess of £60,000 (2021: None)

## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2022 - continued

#### 11. TANGIBLE FIXED ASSETS

	Office equipment £	Database £	Computer equipment £	Totals £
<b>COST</b>				
At 1 April 2021	1,517	31,312	11,282	44,111
Additions	1,037	-	7,186	8,223
At 31 March 2022	<u>2,554</u>	<u>31,312</u>	<u>18,468</u>	<u>52,334</u>
<b>DEPRECIATION</b>				
At 1 April 2021	1,232	31,312	7,421	39,965
Charge for year	159	-	4,094	4,253
At 31 March 2022	1,391	31,312	11,515	44,218
<b>NET BOOK VALUE</b>				
At 31 March 2022	<u>1,163</u>	-	<u>6,953</u>	<u>8,116</u>
At 31 March 2021	<u>285</u>	-	<u>3,861</u>	<u>4,146</u>

#### 12. STOCKS

	2022 £	2021 £
Stocks held for re-sale	<u>6,285</u>	<u>6,256</u>

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

	2022 £	2021 £
Prepayments and accrued income	<u>15,239</u>	<u>8,639</u>

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

	2022 £	2021 £
Social security and other taxes	14,869	11,619
Other creditors	3,810	-
Accrued expenses	13,001	11,138
	<u>31,680</u>	<u>22,757</u>

## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2022 - continued

#### 15. LEASING AGREEMENTS

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

	2022 £	2021 £
Within one year	21,150	21,550
Between one and five years	45,146	67,296
	<b><u>66,296</u></b>	<b><u>88,846</u></b>

#### 16. MOVEMENT IN FUNDS

##### Statement of funds

	Balance b/f at 1.4.21 £	Incoming Resources £	Resources Expended £	Balance c/f at 31.3.22 £
<b>Unrestricted funds</b>				
General funds	443,941	584,340	(479,444)	548,837
<b>Restricted funds</b>				
Support into the 2020s – Lotteries Reaching Communities	10,623	129,324	(111,278)	28,669
Support into the 2020s – Other Grants	-	115,056	(105,056)	10,000
Toy Packs	417	700	(767)	350
Toy packs and Flexible Response Grants	8,574	-	(8,574)	-
Northern Ireland Events	1,655	-	(347)	1,308
PhD Scholarship	-	10,000	(10,000)	-
<b>Total Restricted Funds</b>	<u>21,269</u>	<u>255,080</u>	<u>(236,022)</u>	<u>40,327</u>
<b>TOTAL FUNDS</b>	<b><u>465,210</u></b>	<b><u>839,420</u></b>	<b><u>(715,466)</u></b>	<b><u>589,164</u></b>

## Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
<b>Fund balances at 31 March 2022 are represented by:</b>			
Tangible fixed assets	8,116	-	8,116
Stock	6,285	-	6,285
Debtors	11,951	3,288	15,239
Bank and cash	551,527	39,677	591,204
Current liabilities	(29,042)	(2,638)	(31,680)
<b>Total net assets</b>	<b><u>548,837</u></b>	<b><u>40,327</u></b>	<b><u>589,164</u></b>

### 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's 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 multisensory 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.

### Toy Packs & Flexible Response Grants

This fund covers toy packs as described above and also enables grants to be made to individuals and families affected by SMA. FRGs provide a swift response to an urgent need when no other funding source is available. Grants are typically small. Income in this restricted fund was received as a grant to cover both toy packs and FRGs – to be drawn on flexibly according to need.

### 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

This supports our commitment to fund a 4-year research programme from 2022-2025, jointly with Muscular Dystrophy UK.

## 17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2022.

## Spinal Muscular Atrophy UK

### DETAILED STATEMENT OF FINANCIAL ACTIVITIES for the year ended 31 March 2022

	2022 £	2021 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations and gifts	680,272	539,606
Legacies	25,000	-
Government Grants Covid-19	-	54,295
Community Fund (BLF)	129,342	126,789
	<b>834,596</b>	<b>720,690</b>
<b>Other trading activities</b>		
Merchandise sales	4,694	3,740
<b>Investment income</b>		
Bank interest	130	261
<b>Total incoming resources</b>	<b>839,420</b>	<b>724,691</b>
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Staff costs and other expenses	94,642	106,829
Fundraising and publicity	25,817	24,891
Events and promotions	38,702	11,939
Cost of merchandise sales	2,710	1,954
	<b>161,871</b>	<b>145,613</b>
<b>Charitable activities</b>		
Staff costs and other expenses	342,135	271,585
Research-related Grants	35,072	16,400
Other research activities	6,352	5,189
Information and awareness raising	7,465	5,941
Shared experiences network	27,048	13,009
Outreach Service	37,923	44,957
Welfare, equipment grants and toy packs	29,372	5,193
	<b>485,367</b>	<b>362,274</b>
<b>Support Costs</b>		
<b>Management</b>		
Staff costs and other expenses	48,301	42,103
Professional fees and bank charges	8,939	6,407
Other costs	10,988	13,589
Committee expenses	-	5,356
	<b>68,228</b>	<b>67,455</b>
<b>Total resources expended</b>	<b>715,466</b>	<b>575,342</b>
<b>Net income</b>	<b>123,954</b>	<b>149,349</b>

This page does not form part of the statutory financial statements

## Partnerships & Affiliations

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







**Spinal Muscular Atrophy UK**  
Unit 9, Shottery Brook Office Park  
Timothy's Bridge Road  
Stratford-upon-Avon  
CV37 9NR

**Phone:** 01789 267520

**Email:** [office@smauk.org.uk](mailto:office@smauk.org.uk)  
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**Help for today, hope for tomorrow**

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