

# Annual Report & Financial Statements

For the year ending 31<sup>st</sup> March 2021



 **spinal  
muscular  
atrophy uk**  
Help for today, hope for tomorrow



## 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

For more than a year now, our headlines have been dominated by the global Covid pandemic. The impact on the public has been significant and especially so on the SMA Community. Many of you have faced a year of shielding, stress, and isolation. I hope that during this time, SMA UK has been able to provide support and information that has been of some assistance.

As I write this update, I am heartened by the news that Baby Arthur has become one of the first patients to be treated on the NHS with Zolgensma. This has coincided with the report of zero Covid deaths for the first time since last March. While there may appear to be light at the end of the tunnel, there are still many, many challenges on the horizon. We at SMA UK will continue, amongst other things, to focus our efforts on the campaign for access to the right drugs, support, and care for all those affected by SMA. You can read more about our involvement as well as some of the great outcomes on pages 6 to 10 of this report.

Despite the fact that home visits had to be curtailed, our Outreach & Support service carried on throughout the year, providing individual support in the UK by phone and email to over 200 children, young people and adults who have SMA, and their families. Our website remains an important source of information with more than 84,000 people visiting our site, an increase of almost 20% since 2019. We also added an area dedicated to Covid-related information and responded to your specific questions, working closely with MDUK to channel to leading clinicians. We also started our Community Connections Team, ably led by Martyn Sibley, along with an enthusiastic group of young adults, which provides virtual connections, webinars, videos and now podcasts which further enhances the rich content of information and advice available on our website.

Covid has impacted many aspects of our operation, none more so than fundraising. We were forced to cancel or postpone a number of events and this had the potential to materially impact our finances. However, during the twelve months to 31st March

2021 we benefited from an accelerated payment from the Big Lottery, received support donations from a number of pharmaceutical companies, and made careful use of the government's furlough scheme. Most importantly, we enjoyed tremendous support from the SMA Community. Your overwhelming generosity has meant that our financial position remains sound.

Throughout the year we have been busy improving and strengthening the foundations of SMA UK. I am pleased to report that the Board welcomed 8 new Trustees who bring an exciting range of knowledge and experiences. The work to become a Charitable Incorporated Organisation (CIO) is well underway and in April of this year we lodged our application with the Charities Commission. Finally, I am pleased to introduce you to our new CEO, Angela Morgan-Smith, who started with us in April, too.

I would like to thank all of the retiring Trustees and, especially, my predecessor, Hugo van Vredenburg. His contribution to the charity has been immense. We will miss his thoughtfulness, leadership, wisdom, energy, and, above all, his enthusiasm. In particular, I would like to recognise his extraordinary contribution to our fundraising efforts which included his willingness to get on a bike for a sponsored ride!

Finally, I must thank our extraordinary team at SMA UK, many of whom have worked literally all hours of the day to keep our services going during this very difficult period. I really don't know how you did it! In particular, I want to say a heartfelt thanks to Liz Ryburn, Support Team Manager, and Caroline Dolan, Fundraising Manager for your incredible leadership and unfailing dedication.

Thank you.



**Mark Dearlove, 1st June 2021**

## 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 and that some 71 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, and 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 & Performance

### Our Team

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

We have a small Support Services Team of experienced staff (Claire, Maggie, Michele, Jackie, Jo, Dermot, Libby and Liz, with backgrounds in social work, nursing, occupational therapy, mental health, education and disability-related services – 6.3 FTEs). This year, though, saw the team's working hours much reduced at times due to the impact of Covid-19 on the charity's income.

Our Scientific Research Correspondents always make themselves available to us despite their other work and roles: Dr James Sleight leads his own laboratory research team and Vanessa Christie-Brown is also the SMA Europe Coordinator.

### Outreach and Support



*"Thank you for checking in on us. It's really nice to know that there's a community out there, even though we haven't physically been out for 3 weeks now, we still feel part of it."*  
**Parent of child, family shielding.**

This was a year of shielding, stress and isolation for so many families and adults in the Community.

Children home-schooled, adults working from home, feeling too unsafe to go out, losing jobs and facing financial insecurity,

routine healthcare and monitoring impossible for so many, worries about PAs and carers in the home, and who would have priority with the vaccine roll-out. To have your child diagnosed with SMA when you couldn't be with family and friends would have been shattering.

*"We hugely appreciate all the support the charity has provided to us; it has been a comfort during these dark days."*  
**Parent of a newly diagnosed baby.**

Though we were unable to make home visits for most of the year, we still provided individual support in the UK by phone and email to 207 children, young people and adults who have SMA, and their families. Everyone's circumstances, requests and needs were different with more and more people facing complex and challenging times during the year.

*"...we really appreciate all the help, advice and time you gave us through the whole process we know none of this would have been possible without you guys and can't thank you enough - all going well you can come and see the changes for yourself."*  
**Parent negotiating housing adaptations.**

*"Thank you very much for your support and continued hard work on behalf of us all."*  
**Adult asking advice for a shielding letter.**

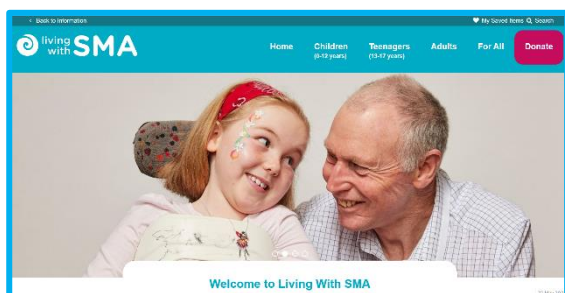
### Information

We also did our best to support the Community by developing a whole website area dedicated to Covid-related information that had 2,450 visitors. We were asked many SMA-specific questions that were worrying people and worked with MDUK to channel these to leading clinicians. We were immensely grateful to the clinicians for responding so quickly, on top of their very stressful caring roles, and were able to keep getting answers out to the Community via our website and social media.

During the year, 84,272 people accessed our website (a 19.5% increase on 2020). Information, Support, and Treatment & Research-related pages in the top ten website page views were:

Page name	Total views 2020
SMA Information	6,776
Support	5,512
About SMA	3,368
Nusinersen	4,106
Zolgensma	4,061
Risdiplam	4,074

We remained accredited to The Information Standard, publishing up to date, evidence-based and accurate information relating to SMA – about the condition and its management, clinical trial results and the new drug treatments.



The ‘Living With SMA’ website section was visited by 2,800 people during 2020. 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 Team. It covers a whole host of topics including health & wellbeing, equipment, homes, education, work, transport, leisure, and financial, emotional and social support.

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

Our monthly E-news bulletin mailing list saw new people sign up. Overall, we saw an increase to just under 3,000 with an opening rate at 28% (2019: 2,900, 26.3% - similar mailings across the sector are 21%). These mailings also kept the Community informed about access to

treatment developments, consultations, surveys, fundraising activities, and other information and news. In October, we took a snapshot of our social media reach:

October	2019	2020
Facebook likes	4,458	4,632
Twitter followers	1,694	2,059
Instagram followers	678	1,136

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 of them 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.

The team also directly supported 67 health, education and social care professionals in their work with people who have SMA.

*“Thank you for all the information, it’s really helpful and some great resources and contacts for me to link in with to try to resolve the situation I was dealing with.”*

**Neuromuscular Care Advisor – advice on transport / car seats for under 3s.**

As members of the UK-wide SMA REACH paediatric and adult clinical networks of professionals from specialist centres, we keep in touch with many more who keep us up to date with developments and the challenges they are facing – which were huge this year. In turn, we keep them informed about issues we are seeing and what we can do to assist.

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

## Multisensory Toy Packs

This year, though we only had 18 requests for these packs for infants aged up to 12 months of age, each one was welcomed by families who were coping not only with the distress of their child's diagnosis but also Covid and their isolation.



*"Thank you so much, it is clear a lot of care and consideration has gone into providing toys for throughout the day, playtime, bath time and bedtime. My baby loves the toys and plays with them every day."*

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

## Connecting With Others

With the possibility of our long planned face-to-face events out of the question (a family day in London in April 2020, and, in August 2020, the first ever national weekend event for adults to get together and then to be joined by families), we had to think fast to set up new opportunities and do all we could to help reduce the social isolation of the year and the impact of this on people's mental health and wellbeing.



We were delighted to invite Martyn Sibley and an enthusiastic group of young adults to become our 'Community Connections Team' and join us in setting up virtual connections and chats.

Access to treatment, especially how it would be impacted by Covid, was a hot topic, so we started with a health and wellbeing webinar series, with Martyn hosting community webinars with leading UK clinical experts. Other members of the group hosted a wide range of other sessions from: 'Preparing for Uni' to 'Having SMA and becoming a parent', to 'Parents: Ask us anything!'. All were released on social media and have a more permanent home on our Living With SMA pages. There were also several virtual socials - not quite like the real thing, but very much enjoyed by those who did drop in.

Virtual networks also proved to be a lifeline for many - the Adult Facebook Group, Young Adults Network, and one for Community Questions where people aged 18+ affected by SMA share what has worked for them, their tips and ideas.

[smauk.org.uk/connect-with-others](https://smauk.org.uk/connect-with-others)

## Advocacy For SMA

Throughout the year, we worked with many other patient groups, alliances and clinicians on Covid-related issues. This included advocating for people with SMA at risk to be on the extremely vulnerable list and able to access the support they needed to shield. We also advocated for them to be high on the vaccine priorities list, along with their families and carers, and for safe vaccines for children at risk to be made available as quickly as possible. Our support work continues on the many other impacts of the pandemic on family income, mental health, education and access to routine healthcare.

Advocacy for **access to drug treatments** didn't stop. Notably, this year, the National Institute of Health and Care Excellence (NICE) announced that it would conduct an evidence review to see if there should be any change to their recommendation that had limited access to nusinersen for those who have SMA Type 3.



We were grateful to the people who had been affected by this for responding to our surveys about the impact it had had on them. We also heard from people who had had access in other countries about the positive impact treatment had had for them and from families with children in the UK who had access, but treatment would stop if their child didn't gain the ability to walk 5 steps within a year. We were able to submit all this evidence via Biogen to NICE. Clinicians and other groups also gathered and submitted their findings.



The outcome of NICE's decision wasn't known until May 2021, but as this was so momentous for so many, we have to mention here that the recommendation was changed to give access to all who have SMA Type 1, 2 or 3 for whom nusinersen is a clinically safe option.

We continued to work collaboratively with other members of the Managed Access Agreement Oversight Committee, including clinicians and representatives from NICE, NHS England, MDUK and TreatSMA, to monitor the roll-out of nusinersen treatment.

NHS England and Centres that had already started the programme gave it high priority, adjusting monitoring and delivery so that it could continue as safely as possible. Adult delivery, however, faltered badly and though in many areas this was due to the impact of Covid on all hospital services, this was not always the only reason. We therefore worked with others to try to uncover and address what other issues were causing delays.

This year inevitably saw delays in both NICE and the Scottish Medicines Committee (SMC) appraisals of the clinical and cost-effectiveness of all treatments for

all conditions. These did, though, start for the gene therapy onasemnogene abeparvovec (Zolgensma™). We gathered community views, wrote joint submissions with MDUK and were patient experts at committee hearings.



Again, it's impossible not to mention here that in April 2021 this one-time gene therapy was given the green light for treating eligible children who have SMA Type 1 for whom it is clinically safe, and also for pre-symptomatic children.

For many who have SMA Type 1 or 2, news of the Compassionate Use Programme (CUP) followed by the UK Early Access to Medicines Scheme (EAMS) for the oral treatment risdiplam was huge. This could be prescribed to those for whom the licensed treatment nusinersen was not clinically suitable.



Yet again, though, this left those diagnosed with SMA Type 3 behind. At this stage, those who had lost walking ability couldn't access nusinersen and no one diagnosed with SMA Type 3 could access risdiplam as these schemes are only provided when a condition isn't life threatening – with SMA Type 3 not considered to be so.

In October, with input from 137 people in the Community who responded to our survey about risdiplam, we again made a joint submission to NICE which had begun its appraisal process.

We argued strongly that the key outcome people are looking for is stabilisation of their condition and that fine motor skills, fatigue levels and impact on breathing are of far more value in the day to day lives of many than the ability to walk. We also argued that the clinical classifications and 'Typing' of SMA was introduced in 1990 by a committee of clinicians and geneticists to promote collaborative studies between different centres and to identify the genes of SMA. It was never designed to be a barrier to access to treatment – and should never be so.

We included in our submission that consideration should be given to the 1% of those diagnosed each year as having SMA Type 4, for whom there is no drug treatment. However, as none of the treatments, thus far, have received licensing authorisation for this group, it has not been possible for the UK regulatory authorities to address this.

With clinical trials and real-world evidence now all showing that early treatment is necessary to maximise the potential benefits of treatment, and pre-symptomatic treatments now available, newborn screening will take centre stage again next year.

In the meantime, clinicians who are part of the UK SMA Newborn Screening Alliance continued their work to prepare pilot studies that will provide the evidence that will be needed. We also worked with SMA Europe and the European Newborn Screening Alliance on their preparations to make this one of their major campaigns.



For more information on all these topics:  
[smauk.org.uk/treatments-research](http://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.

It was with great regret that, due to the impact of Covid-19 on both MDUK and our funding, we were unable to progress the planned SMA PhD Partnership funding. In March, however, we were able to announce our intention to jointly fund one four-year scholarship to start later in 2021.

In the meantime, we have joined with others to highlight the massive impact Covid-19 is having on all research and clinical trials.

We were able to maintain our commitment to 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. This is our last year supporting the registry as finally its value has been recognised and funding will now be provided via pharmaceutical grants.

## SMA Europe



We remained active members of this umbrella organisation of SMA patient and research groups. With 19 member countries, it is a vital network that is progressing many areas of work seeking to elevate the patient voice by empowering member organisations to advocate and campaign at a national level and by harnessing the network to advance research and influence stakeholders at a European level.

Funding of SMA Europe's research call was also put on hold by all countries this year. We are hoping that by the end of 2021 we will be able to contribute again.

[www.sma-europe.eu](http://www.sma-europe.eu)

## Thank you to the Community

Whilst the impact of Covid-19 was felt by everyone this year and income fell, it is only thanks to the kindness and generosity of our supporters that the charity was able to continue to deliver its services in these challenging times.

We are extremely grateful to everyone who kindly made donations of all sizes and came up with ever more inventive ways to raise funds. From those who donate monthly, to marathon runners and schools and businesses who fundraise, every penny counts, and collectively has made a huge impact.

The SMA Community once again showed support through our virtual event, Marathon in May for SMA, and The Big Give Christmas Challenge. This was especially appreciated when so many people were experiencing the impact of Covid-19 on their lives.

With a gap in income left by the cancellation of so many events, we are particularly grateful to organisations that provided support including AveXis (now Novartis Gene Therapies), Biogen and Roche.

Grants from charitable trusts proved once again to be a vital source of income, as was our funding from The National Lottery Community Fund.

We look forward to continuing to work with the SMA Community and all our supporters in the coming year.



## Thank you to Trusts and Companies

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



HM Government

In partnership with

THE NATIONAL LOTTERY  
COMMUNITY FUND

## Report of the Trustees for the year ended 31 March 2021

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 2021. 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 - 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 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. 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 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**

<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> M E Fenton (resigned 30.9.20), Dr H Sobati (resigned 30.9.20), Dr D R Hopkins (resigned 9.7.20), H H C Van Vredenburch (resigned 1.2.21), T J D Sheffield, C S B Knight, Mrs D J Waltier, Dr R Quinlivan, T J Mildon, M T Dearlove, Mrs K M Jackson, M P Collins (appointed 26.11.20), B M O Morris (appointed 26.11.20), Ms L E J West (appointed 26.11.20), Dr A M E Smith (appointed 26.11.20), Dr A M Childs (appointed 26.11.20), Mrs K Y Edwards (appointed 26.11.20), J M Fiorentini (appointed 26.11.20), S Madipalli (appointed 26.11.20), Miss C M Gray (appointed 26.11.20)	
<b>Company Secretary</b> Mrs E Ryburn	
<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 ..... and signed on the Board's behalf by:

**8<sup>th</sup> July 2021**



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

## Treasurer's Report

In common with many charities, this has been a difficult year for SMA UK from a financial point of view, as a result of the challenges to fund raising in the environment of the Covid-19 pandemic.

Income for the year was £721k - a decrease of nearly 22% on the prior year. This was driven, primarily, by the reduction in funds from Trustee and community fundraising events which have not been possible due to Covid restrictions. The charity has, however, benefitted from continued Lottery funding as well as pharmaceutical and Trust support and our Fundraising Team have worked tirelessly on virtual events which have mitigated the drop in donation income.

The total pharmaceutical funding received during the year was £112k which was 15.6% of total income as compared to 6% in the prior year. Specific donations received in 2020/21 were £40,000 from AveXis, £39,124 from Biogen and £33,200 from Roche. We are very grateful for the pharmaceutical support of our core services and Community Connections work at a time when fundraising income was severely impacted as a result of Covid-19. 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 - 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 took a number of steps to reduce costs in response to the impact of the pandemic. Fundraising expenditure for in-person events was reduced saving £121k. A cautious approach was also taken to research activities, in order to conserve funds during the pandemic, resulting in a year-on-year expenditure reduction of £70k. The charity benefited from Government furlough and Covid support schemes amounting to £54k during the year, in order to mitigate staff costs. In addition, SMA UK has moved to new, more cost-effective premises

and renegotiated office infrastructure contracts which put it on an efficient basis going forward.

The total result of these cost control activities was a reduction in expenditure in the year of £272k or 32%. I am also pleased to report that the percentage of our costs that was spent on our charitable purpose, our value in the pound, rose from 56p to 63p as resources were focused on provision of support to the SMA Community.

Our net income for 2020/21 was a surplus of £149k compared to £78k in the prior year. This result has been achieved through the hard work, dedication, and flexibility of all staff under difficult circumstances. The control over activities and conservation of cash mean that the charity is in a good position to resume a more normal level of activity in 2021/22. Even so, the unpredictable impact of the pandemic on the general economy and the pressure on fundraising remains for the coming year. The Board will continue to monitor activities, cash flow projections and reserves very carefully.

I welcome Angela Smith-Morgan as our new CEO and look forward to working with her on the challenges ahead.



**Katharine Jackson,**  
**28<sup>th</sup> June 2021**

# 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 2021 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 2021 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: 8<sup>th</sup> July 2021

**Spinal Muscular Atrophy UK**  
**STATEMENT OF FINANCIAL ACTIVITIES for the Year Ended 31 March 2021**

	Notes	Unrestricted Funds £	Restricted Funds £	2021 Total Funds £	2020 Total Funds £
<b>INCOME &amp; ENDOWMENTS FROM</b>					
Donations & Legacies	2	559,142	161,548	720,690	919,833
Other trading activities	3	3,740	-	3,740	5,262
Investment income	4	261	-	261	775
<b>Total</b>		<u>563,143</u>	<u>161,548</u>	<u>724,691</u>	<u>925,870</u>
<b>EXPENDITURE ON</b>					
Raising funds	5	145,613	-	145,613	267,390
<b>Charitable activities</b>	6				
Provision of support		117,464	190,675	308,139	347,386
Governance costs		67,455	-	67,455	109,102
Pursuit of knowledge		52,885	1,250	54,135	123,939
<b>Total</b>		<u>383,417</u>	<u>191,925</u>	<u>575,342</u>	<u>847,817</u>
<b>NET INCOME/(EXPENDITURE)</b>		179,726	(30,377)	149,349	78,053
<b>Transfers between funds</b>	16	<u>(34,484)</u>	<u>34,484</u>	-	-
<b>Net movement in funds</b>		145,242	4,107	149,349	78,053
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		298,699	17,162	315,861	237,808
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u>443,941</u>	<u>21,269</u>	<u>465,210</u>	<u>315,861</u>

The notes form part of these financial statements

**Spinal Muscular Atrophy UK**  
**Statement of Financial Position at 31 March 2021**

	Notes	Unrestricted Funds £	Restricted Funds £	2021 Total Funds £	2020 Total Funds £
<b>FIXED ASSETS</b>					
Tangible assets	11	4,146	-	4,146	6,113
<b>CURRENT ASSETS</b>					
Stocks	12	6,256	-	6,256	7,835
Debtors	13	8,639	-	8,639	42,191
Cash at bank and in hand		447,657	21,269	468,926	297,484
		462,552	21,269	483,821	347,510
<b>CREDITORS</b>					
Amounts falling due within one year	14	(22,757)	-	(22,757)	(37,762)
<b>NET CURRENT ASSETS</b>		<u>439,795</u>	<u>21,269</u>	<u>461,064</u>	<u>309,748</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		443,941	21,269	465,210	315,861
<b>NET ASSETS</b>		<b>443,941</b>	<b>21,269</b>	<b>465,210</b>	<b>315,861</b>
<b>FUNDS</b>					
Unrestricted funds: General fund	16			443,941	298,699
Restricted funds: Various – see note 16				21,269	17,162
<b>TOTAL FUNDS</b>				<b>465,210</b>	<b>315,861</b>

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

**8<sup>th</sup> July 2021** ..... 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 2021**

	Notes	2021 £	2020 £
<b>Cash flows from operating activities:</b>			
Cash generated from operations	1	172,138	83,135
Net cash provided by operating activities		172,138	83,135
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		(2,574)	(1,105)
Sale of tangible fixed assets		1,617	-
Dividends received		261	775
Net cash used in investing activities		(696)	(330)
<b>Change in cash and cash equivalents in the reporting period</b>		<b>171,442</b>	<b>82,805</b>
<b>Cash and cash equivalents at the beginning of the reporting period</b>		<b>297,484</b>	<b>214,679</b>
<b>Cash and cash equivalents at the end of the reporting period</b>		<b><u>468,926</u></b>	<b><u>297,484</u></b>

**Notes to the Statement of Cash Flows**  
**For the Year Ended 31 March 2021**

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

	2021 £	2020 £
<b>Net income for the reporting period (as per the Statement of Financial Activities)</b>	149,349	78,053
<b>Adjustments for:</b>		
Depreciation charges	2,924	5,830
Dividends received	(261)	(775)
Decrease/(increase) in stocks	1,579	(5,265)
Decrease in debtors	33,552	6,053
Decrease in creditors	(15,005)	(761)
<b>Net cash provided by operations</b>	<b><u>172,138</u></b>	<b><u>83,135</u></b>

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

	At 1.4.20 £	Cash flow £	At 31.3.21 £
<b>Net Cash</b>	297,484	171,442	468,926
Cash at bank and in hand	297,484	171,442	468,926
Total	<u>297,484</u>	<u>171,442</u>	<u>468,926</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:

Improvements to property	20% on cost
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 2021 - continued

#### 2. DONATIONS AND LEGACIES

	2021 £	2020 £
Donations and gifts	539,606	795,531
Government Grants Covid-19	54,295	-
Community Fund (BLF)	126,789	124,302
	<b>720,690</b>	<b>919,833</b>

#### 3. OTHER TRADING ACTIVITIES

	2021 £	2020 £
Merchandise sales	<b>3,740</b>	<b>5,262</b>

#### 4. INVESTMENT INCOME

	2021 £	2020 £
Bank interest	<b>261</b>	<b>775</b>

#### 5. RAISING FUNDS

	2021 £	2020 £
Staff costs and other expenses	106,829	114,642
Fundraising and publicity	24,891	56,459
Events and promotions	11,939	89,631
Cost of merchandise sales	1,954	6,658
	<b>145,613</b>	<b>267,390</b>

## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2021 - continued

#### 6. CHARITABLE ACTIVITIES COSTS

##### Provision of support

	2021 £	2020 £
Staff costs and other expenses	239,038	242,403
Information and awareness raising	5,941	18,218
Shared experience network	13,009	14,163
Outreach Service	44,957	57,256
Information, support and social events	-	-
Welfare and equipment grants	5,194	15,346
	<b><u>308,139</u></b>	<b><u>347,386</u></b>

##### Pursuit of knowledge

	2021 £	2020 £
Staff costs and other expenses	59,119	73,345
Medical research grants	16,251	31,084
Other research activities	5,338	19,510
	<b><u>80,708</u></b>	<b><u>123,939</u></b>

#### 7. SUPPORT COSTS

	2021 £	2020 £
Staff costs and other expenses	42,103	72,467
Professional fees and bank charges	6,407	17,107
Other costs	13,589	15,421
Committee expenses	5,356	4,107
	<b><u>67,455</u></b>	<b><u>109,102</u></b>

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

	2021 £	2020 £
Depreciation – owned assets	2,924	5,830
<b>Fees payable to auditor for:</b>		
- audit	1,500	1,500
- other services	2,995	2,950



**Spinal Muscular Atrophy UK**  
**Notes to the Financial Statements for the Year Ended 31 March 2021 - continued**

**9. TRUSTEES' REMUNERATION AND BENEFITS**

There were no Trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

**Trustees' expenses**

Expenses totalling £nil (2020: £3,338) were reimbursed to nil (2020: 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 £973 (2020: £912)

**10. STAFF COSTS**

	<b>2021</b> £	<b>2020</b> £
Wages and salaries	344,518	362,105
Social security costs	29,811	32,485
Pension	16,108	18,345
	<b><u>390,437</u></b>	<b><u>412,935</u></b>

2020 includes SMA Europe staff costs which SMA UK processes for them and are funded by SMA Europe. From 2021 we continue to do this to support SMA Europe but no longer include this income and expense in our accounts.

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

	<b>2021</b>	<b>2020</b>
Management and administration	1	1
Direct charitable expenditure	8	7
Fundraising and publicity	3	3
	<b><u>12</u></b>	<b><u>11</u></b>

We also engaged contractors in 2021 to assist us with our management and administration 1.2 FTE; 0.1 in fundraising and publicity; 0.1 in direct charitable.

No employees received emoluments in excess of £60,000 (2020: None)

## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2021 - continued

#### 11. TANGIBLE FIXED ASSETS

	Improvements to property £	Office equipme nt £	Database £	Computer equipment £	Totals £
<b>COST</b>					
At 1 April 2020	19,611	4,607	31,312	21,087	76,617
Additions	-	-	-	2,574	2,574
Disposals	(19,611)	(3,090)	-	(12,379)	(35,080)
At 31 March 2021	-	<u>1,517</u>	<u>31,312</u>	<u>11,282</u>	<u>44,111</u>
<b>DEPRECIATION</b>					
At 1 April 2020	19,611	4,217	31,312	15,364	70,504
Charge for year	-	104	-	2,820	2,924
Eliminated on disposal	(19,611)	(3,089)	-	(10,763)	(33,463)
At 31 March 2021	-	1,232	31,312	7,421	39,965
<b>NET BOOK VALUE</b>					
At 31 March 2021	-	<u>285</u>	-	<u>3,861</u>	<u>4,146</u>
At 31 March 2020	-	<u>390</u>	-	<u>5,723</u>	<u>6,113</u>

#### 12. STOCKS

	2021 £	2020 £
Stocks held for re-sale	<u>6,256</u>	<u>7,835</u>

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

	2021 £	2020 £
Prepayments and accrued income	<u>8,639</u>	<u>42,191</u>

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

	2021 £	2020 £
Social security and other taxes	11,619	10,956
Other creditors	-	13,044
Accrued expenses	11,138	13,762
	<u>22,757</u>	<u>37,762</u>

## Spinal Muscular Atrophy UK

### Notes to the Financial Statements for the Year Ended 31 March 2021 - continued

#### 15. LEASING AGREEMENTS

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

	2021 £	2020 £
Within one year	21,550	29,865
Between one and five years	67,296	88,846
	<b><u>88,846</u></b>	<b><u>118,711</u></b>

#### 16. MOVEMENT IN FUNDS

##### Statement of funds

	Balance b/f at 1.4.20 £	Incoming Resources £	Resources Expended £	Funds Transfer	Balance c/f at 31.3.21 £
<b>Unrestricted funds</b>					
General funds	<u>298,699</u>	<u>563,143</u>	<u>(383,417)</u>	<u>(34,484)</u>	<u>443,941</u>
<b>Restricted funds</b>					
Support into the 2020s – Lotteries Reaching Communities	-	126,789	(153,457)	37,291	10,623
Support into the 2020s – Other Grants	-	-	-	-	-
Toy Packs	1,727	-	(1,310)	-	417
Research - Robert Luff Foundation	1,250	-	(1,250)	-	-
Toy packs and Flexible Response Grants	8,860	-	(286)	-	8,574
Northern Ireland Events	1,655	-	-	-	1,655
Community Connections	-	34,759	(31,952)	(2,807)	-
<b>Total Restricted Funds</b>	<u>17,162</u>	<u>161,548</u>	<u>(191,925)</u>	<u>34,484</u>	<u>21,269</u>
<b>TOTAL FUNDS</b>	<b><u>315,861</u></b>	<b><u>724,691</u></b>	<b><u>(575,342)</u></b>	-	<b><u>465,210</u></b>

## Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
<b>Fund balances at 31 March 2021 are represented by:</b>			
Tangible fixed assets	4,146	-	4,146
Stock	6,256	-	6,256
Debtors	8,639	-	8,639
Bank and cash	447,657	21,269	468,926
Current liabilities	(22,757)	-	(22,757)
<b>Total net assets</b>	<b><u>443,941</u></b>	<b><u>21,269</u></b>	<b><u>465,210</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.

### Spinal Muscular Atrophy UK

#### Notes to the Financial Statements for the Year Ended 31 March 2021 - continued

## 16. MOVEMENT IN FUNDS - continued

### Support into the 2020s

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 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.

### 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.

### **Toy packs & Flexible Response Grants**

This fund covers both purposes as described above. It was received as a grant combining both so was set up separately to allow it to be drawn on flexibility 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 have fun.

### **Community Connections**

This project was set up in response to the changes faced by the SMA community and SMA UK due to the impact of Covid 19. In particular it aimed to:

- Help to address the social isolation experienced by people in the SMA community due to Covid-19
- Explore ways to re-set our previous plans to deliver face to face information and support events
- Deliver the virtual events and interactive resources wanted by the community.
- Begin to establish a firm virtual presence so that virtual communication options form part of how SMA UK and the SMA community stay connected

The project was seed funded by Roche and continued through to January 2021 with Lottery Covid 19 funding.

## **17. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 31 March 2021.

## Spinal Muscular Atrophy UK

### DETAILED STATEMENT OF FINANCIAL ACTIVITIES for the year ended 31 March 2021

	2021 £	2020 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations and gifts	539,606	795,531
Government Grants Covid-19	54,295	-
Community Fund (BLF)	126,789	124,302
	<b>720,690</b>	<b>919,833</b>
<b>Other trading activities</b>		
Merchandise sales	3,740	5,262
<b>Investment income</b>		
Bank interest	261	775
<b>Total incoming resources</b>	<b>724,691</b>	<b>925,870</b>
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Staff costs and other expenses	106,829	114,642
Fundraising and publicity	24,891	56,459
Events and promotions	11,939	89,631
Cost of merchandise sales	1,954	6,658
	<b>145,613</b>	<b>267,390</b>
<b>Charitable activities</b>		
Staff costs and other expenses	271,585	315,748
Medical research grants	16,400	31,083
Other research activities	5,189	19,511
Information and awareness raising	5,941	18,217
Shared experiences network	13,009	14,163
Outreach Service	44,957	57,258
Welfare, equipment grants and toy packs	5,193	15,345
	<b>362,274</b>	<b>471,325</b>
<b>Support Costs</b>		
<b>Management</b>		
Staff costs and other expenses	42,103	72,467
Professional fees and bank charges	6,407	17,107
Other costs	13,589	15,421
Committee expenses	5,356	4,107
	67,455	109,102
<b>Total resources expended</b>	<b>575,342</b>	<b>847,817</b>
<b>Net income</b>	<b>149,349</b>	<b>78,053</b>

This page does not form part of the statutory financial statements



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CV37 9NR

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- Mon – Thurs (9.00am – 3.30pm)
- Friday (9.00am – 1.00pm)
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**[www.smauk.org.uk](http://www.smauk.org.uk)**



**Help for today, hope for tomorrow**