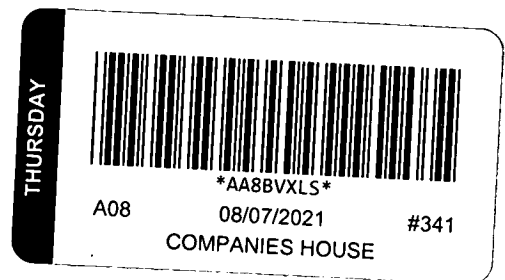


**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES  
REPORT OF THE TRUSTEES AND  
AUDITED CONSOLIDATED FINANCIAL STATEMENTS FOR THE YEAR ENDED  
31 DECEMBER 2020**



**REGISTERED COMPANY NUMBER: 7726882 (England and Wales)  
REGISTERED CHARITY NUMBER: 1143472 / SCO41012**

**M C** **McLINTOCKS**  
**□ L** **CHARTERED ACCOUNTANTS  
AND BUSINESS ADVISORS**  
A Xeinadin Company

# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **REFERENCE AND ADMINISTRATION DETAILS** **for the Year Ended 31 December 2020**

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#### **Trustees & Directors**

Katy Joanne Brown

Appointed 28 November 2020

Sarah Burgess

Judith Mary Evans

James Henry Garthwaite

Dr Gordon Robert Harvey

Prof Atul Bhanu Mehta

David Maurice Patton

Phillip John Pearson

Wilma Robins

Dr Fiona Jane Stewart

Appointed 4 April 2020

Bryan Gordon Winchester

#### **Registered Company number**

7726882 (England and Wales)

#### **Registered Charity number**

1143472 / SCO41012

#### **Registered office**

MPS House, Repton Place, White Lion Road, Amersham, Buckinghamshire, HP7 9LP

#### **Company Secretary**

Robert Stevens

#### **Group Chief Executive Officer**

Robert Stevens

#### **Auditors**

McLintocks (NW) Limited, 2 Hilliards Court, Chester Business Park, Chester, CH4 9PX

#### **Bankers**

Barclays Bank plc, United Kingdom House, 7th Floor, 180 Oxford Street, London, W1B 1EA

#### **Solicitors**

Womble Bond Dickinson, Broad Chare, Newcastle Upon Tyne, NE1 2HF

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **CHAIRMAN'S STATEMENT for the Year Ended 31 December 2020**

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2020 has been a year like no other. The threat of COVID-19 had profound impacts on our members, many of whom are in the 'highly vulnerable' category. Many individuals and families had to shield for months, having to manage the mental and physical challenges of lockdown. At the same time, they had to cope with complex medical conditions, often without the vital face-to-face support that they depend upon. Many hospital appointments and operations were cancelled, home infusions became very complex to arrange, and other support services were reduced. As a result of these challenges, our members needed our support more than ever, and continue to do so in 2021.

The Society rose to the challenge by delivering a real step-change in service. This was possible thanks to the remarkable efforts of the staff team. None were furloughed and, with the Society's offices shut from mid-March, many worked extra hours to support members. They did this without the support and camaraderie that has always been so precious in the office and while coping with the impact of COVID on their own families. I speak on behalf of all of our members in giving heartfelt thanks to 'team MPS' for all that they did in the year.

Through the pandemic more than 1,000 members and their families were contacted and offered additional support. All face-to-face and clinic visits were also made virtually by members of our Advocacy and Support team. This team continues to provide invaluable support, by phone and video-conference, from 7am to 10pm seven days a week.

To help families desperate to understand the implications of COVID and lockdown, we offered a programme of webinars providing the latest information, answering questions and building connections. In total, we delivered 16 webinars which were very well received, with the most popular attracting more than 1,100 views on our website. The website also provided up-to-date and specific guidance about COVID-19 for those with an inherited metabolic disease and signposted families to the most relevant NHS and government advice.

A sense of community is vital in difficult times and, despite our entire 2020 events programme being postponed, we were determined to bring our members closer together. We ran a series of online 'Events for All', from quizzes to scavenger hunts, cooking lessons and a Christmas Panto, all helping to reduce feelings of isolation. We also launched a 'Treats for All' programme, offering vouchers to members providing them with some much needed light-hearted relief. Regular social media posts helped to ensure that families felt part of an increasingly supportive and vibrant society. Since the start of the pandemic, we have had a huge increase in visits to the website relative to the previous years.

We are enormously grateful to our donors who helped ensure that we had the funding necessary to get through this difficult year. Overall, the charity made a significant surplus helped by a contribution of £350,000 from MPS Commercial trading as Rare Disease Research Partners ('RDRP'). RDRP is a business that provides services to the rare disease community and is wholly owned by the MPS Society. The majority of this surplus has been designated by the Board of Trustees to address two rapidly emerging needs in 2021 - mental health and community resilience.

During the year we also made further funds available for research projects. The Board awarded grants for two projects: the first for research into the use of a digital microfluidics platform for the rapid assessment of lysosomal enzyme activity; the second to research how hydrotherapy can help alleviate pain and improve mobility in patients with MPS conditions. We look forward to many more research grant applications in the coming year.

Looking ahead we know that the pandemic will pass but, with funding diverted to COVID-related programmes, ultra-rare diseases face a particularly challenging climate in the UK.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **CHAIRMAN'S STATEMENT for the Year Ended 31 December 2020**

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Despite the inevitable consequences on Government policy and budgets, we are working to ensure that all our community have access to:

- Exceptional support and advice
- World class clinical care; and
- Effective treatments.

In the coming years, the role of the Society, working with the broader Lysosomal Storage Disease (LSD) community in the UK and worldwide, will be more important than ever. We can take encouragement from knowing that, against all the odds, the MPS Society finished 2020 better connected and better resourced to take on that challenge.



**James Garthwaite, Chair of Trustees**

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020**

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The trustees (who are also the directors of the charity for the purposes of the Companies Act) present their report together with the audited financial statements of the Society for Mucopolysaccharide Diseases (the charity and the group) for the year ended 31 December 2020.

The financial statements have been prepared in accordance with the accounting policies set out in note to the financial statements and comply with the Charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)".

#### **OBJECTIVES AND ACTIVITIES**

##### **Principal activity**

To support individuals affected by Mucopolysaccharide diseases, Fabry and related lysosomal diseases, their families and professionals who care for them through partnership working, implementation of the individual advocacy service, increasing awareness and raising funds for research into these diseases.

##### **Objectives and aims**

- affected people know where to turn for specialist knowledge, support & advocacy
- provide services that beneficiaries tell us they need, in a way that suits them
- take an active role in research
- families receive the fastest possible diagnosis
- champion new & existing treatments & therapies
- making it happen by investing in our future

In order to carry out these objectives:

- raise the profile of the organisation to ensure that every affected person in the UK can have easy access to our services
- keep listening to our community and ensure that we provide a tailored, people-led service
- fund and collaborate on innovative, world-class research that could make a positive impact on the lives of those affected
- work in collaboration with other organisations exploring earlier diagnosis
- engage with relevant regulatory organisations to ensure patients are put first
- ensure all members of the MPS Society team have the skills and resources they need

To achieve these objectives, we rely on:

- funding from voluntary donations, corporate donors, charitable trusts and foundations
- support from the public who fundraise and take part in events

##### **What are MPS and related lysosomal diseases?**

MPS and related diseases are rare diseases affecting one baby born every 8 days in the United Kingdom.

MPS and related diseases are a group of 25 rare metabolic diseases, referred to as MPS I, II, III, IV, V, VI and VII, or more commonly, by the name of the doctor who first described the condition: Hurler, Hurler Scheie, Scheie, Hunter, Sanfilippo, Morquio, Maroteaux Lamy and Sly.

Mucopolysaccharidoses and other storage diseases also covered by the Society are: MLI, MLII (I cell disease), MLIII (Pseudo Hurler Polydystrophy), MLIV, Sialidosis, Fucosidosis, Mannosidosis, Sialic Acid Storage Disease, Multiple Sulphatase Deficiency, Aspartylglycosaminuria, Winchester, Metachromatic Leukodystrophy, LaLD (Lysosomal Acid Lipase) and Fabry disease.

Children born with a MPS or related disease are unable to produce enzymes essential for the continual process of breaking down and replacing used materials. Babies may show no sign of the disease, but as more and more cells become damaged by the storage of used material, symptoms begin to appear. Sadly, these are progressive diseases which lead to an increase in problems as the years go by. Effects of the disease vary but are all associated with progressive physical disability. Over half these diseases cause degeneration of the brain resulting in severe learning difficulties and death in childhood.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020**

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#### **OBJECTIVES AND ACTIVITIES (continued)**

##### **Public benefit**

Over the reporting year the Society for Mucopolysaccharide Diseases has worked towards its charitable objectives in the best way it can but due to the COVID-19 pandemic these have had to be adapted in the following ways:

- From point of contact we have provided emotional support, practical advice, information and guidance, signposting to other resources where needed.
- All face to face visits and clinic visits have been made virtual with our Advocacy and Support team offering video call support.
- All members of our community were emailed the direct contact details of each of our Support Workers with additional out of hours contact details. This means that our community have access to our support every weekday and weekend, 7am-10pm.
- We updated our website, offering up-to-date specific guidance for those with an inherited metabolic disease and COVID-19. In addition, we are signposting to NHS and government advice.
- Delivering regular webinars to answer our communities COVID-19 questions, the first webinar held in association with the LSD collaborative was delivered to over 500 participants.
- We supported the NHS and healthcare professionals through running webinars with the Lysosomal Storage Disease (LSD) Collaborative which involve a panel of leading clinicians answering questions and providing information to support healthcare professionals to deliver infusions and treatments in the patients' homes.
- Unfortunately, we made the difficult decision to postpone all of our support events however ran a series of events and exert meetings online, more about this later.

Maintaining our external commitments to support and ensure the patients voice remains paramount with public bodies such as National Institute of Health and Care Excellence (NICE) NHS England and the European Medicines Agency (EMA)

- to be active members of the wider patient community including the UK LSD collaborative, MPS Europe and the International MPS Network
- continuing to support patients participating in clinical trials across 15 countries
- increasing our research and survey work ensuring where possible this is shared publically through posters and publications

The trustees confirm that they have complied with the duty in Section 4 of the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

##### **Fundraising**

The MPS Society is registered with the Fundraising Regulator and as such adheres to their Code of Fundraising Practice. We promote our registration with the regulator on our materials and website and our Fundraising Promise is available on the website. This promise outlines our commitment to donors and the public to uphold the high standards and best practice expected of those charities registered with the Regulator.

We do not have any agreements with external fundraising companies or mailing companies for the purposes of fundraising or marketing. We do not buy in mailing lists for direct marketing, nor do we pass on our supporters' information to third parties except in circumstances such as registering them for an external event, which by definition has their explicit consent. All of our fundraising activity is managed by the Head of Fundraising & Communications who takes responsibility for any issues arising from those who are fundraising on our behalf.

As part of our General Data Protection Regulation (GDPR) compliance we have ensured that our approaches to past supporters adhere to our Data Retention Policy and Privacy Policy and we do not approach anyone who would not reasonably expect to hear from us through past engagement with support activity. All communications will include the opportunity to opt out as well as state what form of communication is appropriate.

## SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

### TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020

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#### ACHIEVEMENTS AND PERFORMANCE

Our priority, as ever, is to the families we support, our team, volunteers and supporters. Our commitment to ensuring that every person affected by an MPS or related disease has access to a supportive community has been more important than ever due to the COVID-19 pandemic.

##### Impact on our community

MPS and related diseases are multi-organ storage diseases which cause progressive physical disability and, for more than half, accelerated progressive neurological degeneration. The majority of our members are classed as more 'at risk' of COVID-19 under current NHS guidance. This is currently still having major implications on the families we support including:

- **Threat to life:** Coronavirus poses a severe threat to life for our community and, understandably, the families we support are particularly anxious about protecting their loved ones from contracting the virus. For most, this means strict self-isolation.
- **Social isolation:** Social isolation and distancing means that many of our members feel lonely and isolated. Disruption to routine can be particularly challenging for our younger members and those with neurological degeneration and/or learning disabilities. This can lead to increased challenging behaviours and outbursts for these members who are frustrated and trying to understand what is going on.
- **Limited independence:** Independence is a key issue for our members who will struggle with having to rely on others for support with everyday tasks outside the home, such as shopping, commuting, work etc., that they are used to doing themselves.
- **Challenges for parents and carers:** The majority of our community rely on parents, family and partners for their personal care. Social distancing increases care responsibilities as day groups, schools and workplaces close. Carers will now have to juggle 24/7 care responsibilities with their jobs; caring and home-schooling their other children; housework and any other responsibilities with little to no respite.
- **Disruption for siblings:** Siblings of children with an MPS or related disease are also affected. The demanding physical and emotional needs of affected members means that siblings may have to help with care, home-school alone and entertain themselves in the home. This can be particularly isolating and disruptive for younger siblings.
- **Cancelled treatments:** There is no cure for MPS and related diseases, but many members rely on regular enzyme replacement and other therapies and treatments to alleviate or reduce symptoms. With the demand on the NHS, treatments are being cancelled and our members are encouraged to not attend any 'non-essential' appointments to limit their chances of contracting the virus. This means that our member's condition may deteriorate and symptoms worsen.
- **Medical research:** The pandemic has had an impact on current and planned medical research programmes as participants will be unable to attend appointments and healthcare professionals will be drafted into Coronavirus emergency response. This will be disruptive with some research programmes being paused and others needing to be started again after the outbreak is under control.
- **NHS implications:** Where possible, those with MPS and related diseases will receive any clinical care or treatment in their own home to minimise risk of coming into contact with contagions. With the current demand on the NHS, this means that many of the healthcare professionals treating our community will be unfamiliar with this rare group of diseases. In addition, carers and parents are going to be increasingly relied on to administer some treatments, medications and injections.

##### Impact on our services

Due to the changing situation with the COVID-19 outbreak, the MPS Society took the decision to close our office and ask staff to work remotely from mid-March. We took steps to make sure the services we offer continued to run as normal as possible and adapted to meet the changing needs of our members during the outbreak.



## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020**

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#### **ACHIEVEMENTS AND PERFORMANCE (CONTINUED)**

##### **Our vital support services for the MPS & related diseases community across 2020**

Our Advocacy & Support team have continued to provide support to our community by telephone, email, and offering video calls where appropriate. Our team have continued to actively contact our membership to offer support and reassurance, to provide a listening ear in order to reduce feelings of isolation and anxiety, and to offer advice and signposting to relevant information. Since the start of the outbreak the Support and Advocacy team have been in contact with **over 1,000** individuals regarding COVID-19. This has included answering queries and concerns, ongoing case support and regular catch ups with our young people.

##### **Events and expert meetings**

- We carried out an Expert Consensus meeting on self-directed action for those with lysosomal storage diseases during times of high levels of community transmission of COVID-19. We plan to review existing literature on clinically vulnerable populations and bring together a group of expert clinicians from the UK LSD centres to share experiences, discuss the evidence and put forward recommendations for this community in the event of future high levels of transmission of coronavirus.
- In October we ran a "Rare of the Rare" online Expert Meeting featuring a range of expert speakers and 40 online delegates, exploring topics specifically relating to those we support in the ultra-rare diseases community, including Metachromatic Leukodystrophy, Multiple Sulphatase Deficiency, Fucosidosis and the Mucopolysaccharidoses. The programme included a family speaker to give their perspective on their journey through ultra-rare disease; feedback on research carried out by the Rare Disease Research Partners arm of the MPS Society into the patient experience of these diseases; diagnosis of these conditions, genetics & diagnostic testing; exploring the natural history of these diseases; best practice protocols; and breakout groups on particular topics to plan the next steps of what work can be undertaken in these areas. We are now looking at various projects to be taken forward such as clinical guidelines.
- To bring our community together and provide them with some much-needed fun and entertainment, we launched "Events for All", a series of online activities tailored to the interests of our members and their families. So far this has included an evening for a group of our bereaved families to chat together, an online Halloween party which was greatly enjoyed by around **20** of our families, and a fun Scavenger Hunt which **10** families took part in. Our "Make a Christmas decoration" event was very popular, with around **30** families attending. We sent out craft kits for the families, to follow our step-by-step guide to make the decorations with us during the session. During the festive season we ran a Christmas Quiz night, an online Christmas party and panto, and other great events which really lifted the spirits of our community.

#### **Fundraising & Communications**

##### **Individual donations**

We are very grateful to our supporters who choose to donate to us monthly. We have also received £45,414.33 donations in memory, of which £34,000 was from one family.

##### **Do your own thing**

We are grateful to our supporters who choose to fundraise for us in many creative ways throughout the year and in 2020 raised **£23,538.63**. This includes a very successful birthday fundraiser for one of our members (£1,300), Marina and Friends (a community shop with proceeds coming to MPS Society) (£6,454.72) and 60 Facebook Birthday Fundraisers (£5,705.03).

##### **Events & Challenges**

We raised **£41,233.82** from challenge events, other sports events, a supporter who is going to trek to Everest Base camp and Active April. The total from the London Marathon in 2020 was a staggering £18,786.28 even though this has to be virtual. One supporter did a solo marathon which raised £7,534.88 and an affected member raised over £1,000 for Active April.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020**

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#### **Fundraising & Communications (continued)**

##### **Christmas Campaign**

The Big Give once again was a great success with many donations coming in from supporters, companies and trusts and raised over £18k.

##### **MPS Awareness Day**

Due to the pandemic our campaign was moved online and had to change direction at short notice. The week raised a total of £2,547.

##### **Trusts & Pharmaceutical**

We would like to extend a big thank you to our key supporters this year who donated emergency funds due to the pandemic, including The Gosling Foundation, Global's Make Some Noise, The Big Lottery and The Julia and Hans Rausing Trust, along with grants from a number of pharmaceutical companies. We were also very grateful to a number of charitable trusts and foundations for their grants and donations towards various aspects of our support services, including: The Masonic Charitable Foundation, the Eveson Charitable Trust, the Summerfield Charitable Trust, the Wixamtree Trust, the Pilkington Charities Fund, the Borrowes Charitable Trust and the Adint Charitable Trust.

##### **Communications**

We carried out regular updates of information on our website, offering up-to-date specific guidance for those with an inherited metabolic disease and signposting to NHS and government advice, as well as regular social media posts to ensure that all of our members continued to feel part of a supportive community. Since the start of the pandemic we have had **18k** visits to the website which was a huge increase compared to the same time over previous years.

We have continued to deliver webinars to our community, providing the latest information, answering questions and building connections. We have delivered **16** webinars so far which have been very well received; one of these webinars has had **1,122** views to date on our website.

#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing document**

The Society is controlled by its governing document, a deed of trust, and constitutes a company, limited by guarantee, as defined by the Companies Act 2006.

The Society was founded in 1982 and was registered with the Charity Commission in 1983 as an *unincorporated association*, registered charity number 287034. On 2 August 2011 the Society incorporated as a company limited by guarantee with the name 'Society for Mucopolysaccharide Diseases'. The assets, liabilities and activities of the Society were transferred into this charitable company on 1 November 2011.

##### **Recruitment and appointment of new trustees**

New trustees are elected by the membership and may hold office for six years.

##### **Induction and training of new trustees**

New trustees are provided with information about the Society and its work, the role and responsibilities of trustees, and the composition and workings of the Board. They are given copies of the Society's governing instrument, a folder of all the Society's policies and the minutes of the last five Board of trustees meetings. Trustees are regularly provided with the latest information on employment and charity law through the provision of the monthly Governance and Leadership magazine.

##### **Pay policy for key management personnel**

The Board of trustees are responsible for defining the Society's pay policy and setting the annual salary for the Chief Executive.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020**

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#### **STRUCTURE, GOVERNANCE AND MANAGEMENT (continued)**

##### **Organisational structure**

The Society is governed by a Board of up to 13 trustees known as the Board of directors which meets a minimum of five times during the year. The day to day business of the Society is managed by the Chair and Vice Chair and is governed by the Articles of Association.

##### **Wider network**

One trustee's first language is Welsh and another lives in Scotland. Geographically, the MPS Society provides a UK wide support and individual advocacy service from MPS House based in Amersham in Buckinghamshire. Our 25 employees are central to providing the support, individual advocacy services and the communication of our cause, while our supporters enable us to achieve our goals and objectives.

##### **Risk management**

The trustees have identified the level of risks to which the Society may be exposed and have established the implementation of a risk management strategy which comprises quarterly reviews of the risks the Society may face, systems and procedures to mitigate these risks and implementation of procedures designed to report on and minimise any potential impact on the Society should any of these risks materialise.

The trustees have given due consideration of the recent events surrounding the outbreak of COVID-19. Whilst the economic and social impact is unknown the trustees have implemented the appropriate procedures to mitigate the impact on the Society.

#### **FINANCIAL REVIEW**

The MPS Society continues to raise and receive funds through applications to grant giving bodies to support its advocacy service and charitable events, including the salaries of the senior advocacy officer and four advocacy officers, as well as special projects. The Society continues to rely heavily throughout the year on its members and supporters' efforts to raise income by way of donations and fundraising. The fundraising receipts in this reporting period were £ 114,794 compared with £93,602 in 2019. Receipts from donations and legacies were £186,832 compared with £164,170 in 2019. This year legacies of £109,377 were received whereas £16,562 legacies were received in 2019.

MPS Commercial Limited is a wholly owned trading subsidiary of the MPS Society. All logistical services related to Patient Access to Clinical Trials and work involving Health Technology Assessments and Patient Reported Outcomes are carried out by MPS Commercial. In 2020, MPS Commercial were able to donate £350,042 (2019: £416,643) to the MPS Society.

Total group income for the year ending 31 December 2020 was £2,055,446 (2019: £1,698,767) compared with total expenditure of £1,513,142 (2019: £1,581,144) resulting in a surplus of £542,304 (2019: £117,623).

The trustees continue to work closely with the Senior Leadership Team to ensure full cost recovery in all areas of work.

##### **Reserves policy**

In the year, ending 31 December 2020 the trustees reviewed the charity's reserves policy to ensure that it is flexible enough to withstand the high and lows of funding, and be robust in its ability to secure the future of our services. In so doing, the trustees agreed to the established policy whereby the unrestricted funds not committed or invested in tangible fixed assets ('the free reserves') held by the charity should be six months of the unrestricted resources. In accordance with good practice, this is reviewed each year to ensure that it fairly reflects the needs of the society. The review in the current year concluded that the current policy of aiming for reserves of six months of the unrestricted resources remains appropriate. Current year our six months overall expenditure equates to £756,571 (2019: £790,572). The level of free reserves as at 31 December 2020 amounted to £745,480 (2019: £744,730) which amounts to 5.9 months of overall expenditure of the society.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020**

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#### **PLANS FOR THE FUTURE**

The MPS Society is facing unprecedented demands and pressures on the services we provide. This comes at a time when the fundraising climate is changing and increasing revenue will be challenging.

As mentioned above, we have identified that a key focus for the MPS Society for the coming two years needs to be the mental health and wellbeing of our community as this is clearly a pressing need. We want to ensure that those living with MPS and related diseases, and their families, feel better equipped to face the many difficulties of life with an MPS or related condition, particularly following the impact of the COVID-19 crisis. We want to provide tailored support and self-help techniques to affected individuals and families, leading to improved mental health and resilience. We are currently scoping out an innovative new outreach programme of support for 2021 – 2022.

Alongside the Mindfulness courses described above, we are planning to offer our members and their families the opportunity to access a series of online sessions with a professional counselling service in order for them to explore and discuss the issues they are facing and how they can work through these and face the future positively. As part of this programme of support we will explore other group activities including workshops and support groups, which would initially need to be online until it is safe to organise these in person. We are also planning to roll out surveys on mental health and wellbeing to better understand the needs of our community and how we can best meet them in ways which they will find most beneficial.

We also have exciting plans including looking at funding a psychological support post within specialised services at one of the UK specialist centres for lysosomal storage disorders, a programme of resilience work with young people living with an MPS or related condition, a programme of sibling support, advance care planning, and bereavement support.

We will continue to provide and adapt our vital support services to our community throughout the rest of the coronavirus crisis and beyond.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2020**

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#### **STATEMENT OF TRUSTEES RESPONSIBILITIES**

The trustees, who are also the directors of Society for Mucopolysaccharide Diseases for the purposes of company law, are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 Statement of Recommended Practice (SORP);
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- 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 adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005. 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.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on MPS Society's website.

#### **AUDITORS**

In accordance with the charitable company's articles, a resolution proposing that McLintocks (NW) Limited be reappointed as auditor of the charitable company will be put at a General Meeting.

#### **Disclosure of information to auditors**

Each of the trustees has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

The trustee's report was approved by the Board of trustees.



James Garthwaite, Chair of Trustees  
For the year ended 31 December 2020

26 June 2021

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES OF THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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#### **Opinion**

We have audited the financial statements of The Society For Mucopolysaccharide Diseases (the 'charitable parent company') and its subsidiaries ('the group') for the year ended 31 December 2020 which comprise the group statement of financial activities, the group balance sheet, the charitable company balance sheet, the group statement of cash flows and the related 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 FRS 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 group's and the charitable company's affairs as at 31 December 2020 and of its incoming resources and application of resources, 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 the Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 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 group and 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.

#### **Emphasis of matter**

We draw attention to note 24 to the financial statements which describes events after the reporting period the group and the charitable company are facing as a result of the ongoing COVID-19 pandemic. Our opinion is not modified in respect of this matter.

#### **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 charity'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 other information comprises the information included in the annual report set, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in this report, we do not express any form of assurance conclusion thereon.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES OF THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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#### **Other information (continued)**

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of the other information, we are required to report that fact.

We have nothing to report in this regard.

#### **Opinion 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, which includes the directors' report for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within 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 environment of the charitable company and the group obtained in the course of the audit, we have not identified material misstatements in the directors' report included within 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; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

#### **Responsibilities of trustees**

As explained more fully in the statement of trustees' responsibilities, the trustees, who are also the directors of the charitable company for the purpose 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.

#### **Auditor's 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 an auditor's report 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.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES OF THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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#### **Auditor's responsibilities for the audit of the financial statements (continued)**

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. The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

Enquiries of management and those charged with governance were held in order to identify any laws and regulations that could be expected to have a material impact on the financial statements. Throughout the audit, the team were updated with the outcomes of these enquiries including consideration as to where and how fraud may occur in the charitable company and the group.

The audit procedures undertaken to address any potential risk in relating to irregularities (which include fraud and non-compliance with laws and regulations) included: enquiries of management and those charged with governance on how the charitable company and group comply with relevant laws, regulations and any cases actual or potential litigation or claims; examination of appropriate legal correspondence; review of board minutes; testing of journal entries for appropriateness; and analytical procedures on account balances to identify variances against expectation which may show indications of fraud.

No instances of material non-compliance were identified, although the prospect of detecting irregularities, including fraud, is inherently difficult. This is due to; difficulty in detecting irregularities; limits imposed by the effectiveness of the entity's controls; and the nature, timing and extent of the audit procedures performed. Irregularities as a result of fraud are inherently more difficult to detect than those that resulting from error. Despite the audit has being planned and performed in accordance with ISAs (UK), there is an unavoidable risk that material misstatements may not be detected.

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.



**Michael Caputo FCA (Senior Statutory Auditor)**  
**For and on behalf of McLintocks (NW) Limited**

26 June 2021

**Chartered Accountants**  
**Statutory Auditor**

2 Hilliards Court  
Chester Business Park  
Chester  
Cheshire  
CH4 9PX

#### **Notes:**

1. The maintenance and integrity of the MPS Society & Rare Disease Research Partners websites is the responsibility of the trustees; the work carried out by the auditors does not involve consideration of these matters and, accordingly, the auditors accept no responsibility for any changes that may have occurred to the financial statements since they were initially presented on the web site.



# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) for the Year Ended 31 December 2020

	Note	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
<b>INCOME</b>					
<i><b>Voluntary income:</b></i>					
Donations & legacies	3	146,265	149,944	296,209	180,732
<i><b>Activities for generating funds:</b></i>					
Charitable activities	4	114,794	595,310	710,104	512,817
Other trading activities	5	1,023,060	-	1,023,060	981,856
Investment income	6	26,073	0	26,073	23,362
<b>TOTAL INCOME</b>		<u>1,310,192</u>	<u>745,254</u>	<u>2,055,446</u>	<u>1,698,767</u>
<b>EXPENDITURE</b>					
<i><b>Raising funds:</b></i>					
Fundraising cost of grants & donations	7	75,892	-	75,892	63,563
Fundraising activities		80,405	-	80,405	74,782
Trading activities		481,193	-	481,193	542,882
		<u>637,490</u>	<u>-</u>	<u>637,490</u>	<u>681,227</u>
<i><b>Charitable activities:</b></i>					
Advocacy services & member events	8	12,297	475,874	488,171	720,761
Awareness raising		124,486	-	124,486	78,517
Trading activities		167,301	-	167,301	-
		<u>304,084</u>	<u>475,874</u>	<u>779,958</u>	<u>799,278</u>
<i><b>Other costs</b></i>	9	95,694	-	95,694	100,639
<b>TOTAL EXPENDITURE</b>		<u>1,037,268</u>	<u>475,874</u>	<u>1,513,142</u>	<u>1,581,144</u>
<b>NET INCOMING RESOURCES</b>		272,924	269,380	542,304	117,623
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		2,366,043	48,670	2,414,713	2,297,090
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u>2,638,967</u>	<u>318,050</u>	<u>2,957,017</u>	<u>2,414,713</u>

The Statement of Financial Activities includes all gains and losses recognised in the year. All income and expenditure has been derived from continuing activities.

The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.


# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## CONSOLIDATED STATEMENT OF FINANCIAL POSITION At 31 December 2020

	Note	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
<b>FIXED ASSETS</b>					
Tangible assets	17	1,089,612	1,089,040	1,123,517	1,121,313
Investments	18	310,897	310,899	306,100	306,102
		1,400,509	1,399,939	1,429,617	1,427,415
<b>CURRENT ASSETS</b>					
Debtors	19	307,159	610,215	666,221	656,754
Cash at bank and in hand	20	2,027,320	1,007,555	851,560	429,153
		2,334,479	1,617,770	1,517,781	1,085,907
<b>CREDITORS</b>					
Amounts falling due within one year	21	777,971	60,692	532,685	98,609
<b>NET CURRENT ASSETS</b>		1,556,508	1,557,078	985,096	987,298
<b>NET ASSETS</b>		2,957,017	2,957,017	2,414,713	2,414,713
<b>FUNDS</b>	23				
Unrestricted Funds:					
General charitable funds		750,000	750,000	752,815	752,815
Property funds		1,084,520	1,084,520	1,113,228	1,113,228
Designated funds		804,447	804,447	500,000	500,000
		2,638,967	2,638,967	2,366,043	2,366,043
Restricted Funds		318,050	318,050	48,670	48,670
<b>TOTAL FUNDS</b>		2,957,017	2,957,017	2,414,713	2,414,713

As permitted by s408 Companies Act 2006, the charitable company has not presented its own statement of financial activities and related notes. The charitable company's surplus for the year was £542,304 (2019: £117,623).

The consolidated financial statements were approved by the Board of Trustees on 26 June 2021 and were signed on its behalf by:

  
James Garthwaite, Chair of Trustees

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## CONSOLIDATED STATEMENT OF CASH FLOWS for the Year Ended 31 December 2020

	Notes	2020 £	2019 £
<b>Cash flows from operating activities:</b>			
Cash generated from operations	1	1,185,958	(21,840)
Interest paid		(5,401)	(3,062)
<b>Net cash provided by (used in) operating activities</b>		<b>1,180,557</b>	<b>(24,902)</b>
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		-	(8,756)
Investment in bonds		(4,797)	(300,000)
<b>Net cash provided by (used in) investing activities</b>		<b>(4,797)</b>	<b>(308,756)</b>
<b>Change in cash and cash equivalents in the reporting period</b>		<b>1,175,760</b>	<b>(333,658)</b>
<b>Cash and cash equivalents at the beginning of the reporting period</b>	2	<b>851,560</b>	<b>1,185,218</b>
<b>Cash and cash equivalents at the end of the reporting period</b>	2	<b>2,027,320</b>	<b>851,560</b>

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

**NOTES TO THE CONSOLIDATED STATEMENT OF CASH FLOWS  
for the Year Ended 31 December 2020**

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

	<b>2020</b>	<b>2019</b>
	<b>£</b>	<b>£</b>
<b>Net income for the reporting period (as per the statement of financial activities)</b>	542,304	117,623
<b>Adjustments for:</b>		
Interest received	5,401	3,062
Depreciation	33,385	40,930
Loss on disposal of fixed assets	520	-
Decrease/(increase) in debtors	359,063	(488,430)
Increase/(decrease) in creditors	245,285	304,975
	<u>1,185,958</u>	<u>(21,840)</u>
<b>Net cash provided by (used in) operating activities</b>	<u>1,185,958</u>	<u>(21,840)</u>

**2 ANALYSIS OF CHANGES IN NET FUNDS**

	<b>2020</b>	<b>2019</b>
	<b>£</b>	<b>£</b>
Cash in hand	2,289	2,472
Bank accounts	2,025,031	849,088
	<u>2,027,320</u>	<u>851,560</u>
<b>Total cash and cash equivalents</b>	<u>2,027,320</u>	<u>851,560</u>

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2020**

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#### **1. ACCOUNTING POLICIES**

##### **Charity information**

The Society For Mucopolysaccharide Diseases is a registered charity and private company limited by guarantee incorporated in England and Wales. The registered office is MPS House, Repton Place, White Lion Road, Amersham, Buckinghamshire, HP7 9LP.

The group consists of The Society For Mucopolysaccharide Diseases and all of its subsidiaries.

The Charitable Company's financial statements have been prepared in compliance with the Charities SORP FRS 102 issued 1 January 2015 (update bulletin 2, effective 1 January 2019).

##### **1.1 Accounting convention**

The Group and Charity financial statements have been prepared in accordance with the Statement of Recommended Practice: "Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (SORP) issued on 16 July 2014 and the "Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland" (FRS 102). They also comply with the reporting requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 and the Charities Act 2011. The charitable company is a Public Benefit Entity as defined by FRS 102. The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of certain financial instruments at fair value. The principal accounting policies adopted are set out below.

The charitable company is a qualifying entity for the purposes of FRS 102, being a member of a group where the parent of that group prepares publicly available consolidated financial statements, including this company, which are intended to give a true and fair view of the assets, liabilities, financial position and profit or loss of the group. The charitable company has therefore taken advantage of exemptions from the following disclosure requirements for parent company information presented within the consolidated financial statements:

- Section 7 'Statement of Cash Flows': Presentation of a statement of cash flow and related notes and disclosures;
- Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instrument Issues': Carrying amounts, interest income/expense and net gains/losses for each category of financial instrument; basis of determining fair values; details of collateral, loan defaults or breaches, details of hedges, hedging fair value changes recognised in profit or loss and in other comprehensive income ;
- Section 33 'Related Party Disclosures': Compensation for key management personnel.

##### **1.2 Basis of consolidation**

The consolidated financial statements incorporate those of The Society For Mucopolysaccharide Diseases and all of its subsidiaries (i.e. entities that the group controls through its power to govern the financial and operating policies so as to obtain economic benefits) on a line-by-line basis.

All financial statements of subsidiaries are made up to 31 December 2020.

All intra-group transactions, balances and unrealised gains on transactions between group companies are eliminated on consolidation. Unrealised losses are also eliminated unless the transaction provides evidence of an impairment of the asset transferred.

## SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

### NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2020

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#### 1. ACCOUNTING POLICIES (CONTINUED)

##### 1.3 Preparation of the accounts on a going concern basis

The trustees have considered the future trading of the charitable company and the group and have prepared cash flow forecasts for a period of 12 months from the date of these financial statements.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charitable company has adequate resources to continue in operational existence for the foreseeable future, despite the COVID-19 global pandemic – see further details in note 24. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

##### 1.4 Incoming resources

Income is stated after trade discounts and other sales taxes.

###### *Voluntary income*

Voluntary income, which is received by way of restricted and unrestricted donations, gifts, legacies and special fund raising events, is included in the SOFA in full as soon as it is received.

###### *Grants receivable*

Grants are recognised when the charity has entitlement to the funds, any performance conditions attached to the items of income have been met, it is probable that the income will be received and the amount can be measured reliably.

###### *Legacies*

Legacy income is recognised when it is certain to be received and can be measured with sufficient reliability.

###### *Donations in kind*

The MPS Society appreciates the level of active support it receives from volunteers who spend a considerable amount of time supporting our objectives, fund raising and administering our activities. Without this voluntary support the MPS Society would incur considerable additional expense. It is not considered practicable for the purposes of these financial statements to put a monetary value on this support; the trustees can but offer their heartfelt gratitude to all its volunteers and supporters. Gifts and intangible income that can be quantified are recognised in the SOFA.

###### *Investment income*

Investment income comprises gilt, building society and bank interest receivable. This is included in the income and expenditure account in the year in which it is received.

###### *Income from other trading activities*

This income is from the trading subsidiary MPS Commercial Limited. This comprises patient management fees and survey research. Income is recognised at the fair value of the consideration received or receivable for goods and services provided in the normal course of business.

##### 1.5 Expenditure

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. Grants payable are included in the SOFA in the year in which they relate. Grants offered subject to conditions which have not been met at the yearend date are noted as a commitment but not accrued as expenditure.

##### 1.6 Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include Head Office costs, finance, personnel, payroll and governance costs. Governance costs are those incurred in connection with administration of the Charity and compliance with constitutional and statutory requirements. These are apportioned based on staff numbers.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2020**

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#### **1. ACCOUNTING POLICIES (CONTINUED)**

##### **1.7 Pass-through costs and reimbursements**

Clinical trial expenditure and reimbursements are not included in the financial statements. Expenditure is incurred by MPS Commercial Limited on behalf of patients participating in clinical trials with costs being reimbursed by the pharmaceutical companies. MPS Commercial Limited acts as an agent on behalf of the pharmaceutical companies (under guidance of FRS 102 section 23.4).

##### **1.8 Fund accounting**

The financial statements distinguish between restricted and unrestricted funds. The former is received from donors and is subject to restrictions on the purposes for which they may be used. Unrestricted funds are those where there are no externally imposed restrictions. They include those funds freely available to the charity for expenditure or appropriation to reserves for internally designated purposes, such as research programmes. Designated funds comprise funds which have been set aside at the discretion of the trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the financial statements.

##### **1.9 Tangible fixed assets**

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Freehold land and buildings	Straight line over 50 years
Computers and equipment	Straight line over 3-4 years

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in income/(expenditure) for the year.

##### **1.10 Fixed asset investments**

A subsidiary is an entity controlled by the charity. Investments in subsidiaries are valued at cost less provision for impairment.

Investment assets arising from donate valuables are included at market value. These assets are valued at open market value at the date of donation and subsequently revalued to open market value as appropriate.

Fixed asset investments in bonds are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

##### **1.11 Debtors**

Debtors are recognised at the settlement amount due after any trade discounts offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

##### **1.12 Cash at bank and in hand**

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the account.

##### **1.13 Creditors and provisions**

Creditors and provisions are recognised where a present obligation results from a past event which will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

##### **1.14 Taxation**

The Society as a registered charity is not considered to be liable to taxation. VAT incurred is not recoverable and is included in relevant expenditure.

## SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

### NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2020

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#### 1. ACCOUNTING POLICIES (CONTINUED)

##### 1.15 Pension costs and other post-retirement benefits

The Society contributes 5% of gross salary to individual employees' pension schemes. Contributions payable to individual defined contribution pension schemes are charged to the SOFA in the period to which they relate.

##### 1.16 Financial Instruments

The charitable company has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charitable company's balance sheet when the charitable company becomes party to the contractual provisions of the instrument. Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

###### *Basic financial assets*

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

###### *Basic financial liabilities*

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised. Debt instruments are subsequently carried at amortised cost, using the effective interest rate method. Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

###### *Derecognition of financial liabilities*

Financial liabilities are derecognised when the charitable company's contractual obligations expire or are discharged or cancelled.

##### 1.17 Critical accounting estimates and judgements

In the application of the Charity's accounting policies, the trustees are required to make judgement, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

#### 2. LEGAL STATUS

The Charity is a company limited by guarantee. The members of the company are the trustees named on page 1. In the event of the Charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the Charity.



# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

### 3. DONATIONS AND LEGACIES

	2020 Unrestricted fund £	2020 Restricted fund £	2020 Total funds £	2019 Unrestricted fund £	2019 Restricted fund £	2019 Total funds £
Donations	146,265	40,567	186,832	164,170	-	164,170
Legacies	-	109,377	109,377	16,562	-	16,562
	<u>146,265</u>	<u>149,944</u>	<u>296,209</u>	<u>180,732</u>	<u>-</u>	<u>180,732</u>

### 4. INCOME FROM CHARITABLE ACTIVITIES

	2020 Unrestricted fund £	2020 Restricted fund £	2020 Total funds £	2019 Total funds £
Advocacy support grants	93,194	561,810	655,004	236,465
Conferences and Expert meetings	-	33,500	33,500	157,750
Family support special events	11,600	-	11,600	25,000
Fundraising events	-	-	-	91,845
Other income	10,000	-	10,000	1,757
	<u>114,794</u>	<u>595,310</u>	<u>710,104</u>	<u>512,817</u>

### INCOME FROM CHARITABLE ACTIVITIES – 2019 COMPARATIVES

	2019 Unrestricted fund £	2019 Restricted fund £	2019 Total funds £
Advocacy support grants	-	236,465	236,465
Conferences and Expert meetings	-	157,750	157,750
Family support special events	-	25,000	25,000
Fundraising events	91,845	-	91,845
Other income	1,757	-	1,757
	<u>93,602</u>	<u>419,215</u>	<u>512,817</u>

### 5. OTHER TRADING ACTIVITIES

	2020 £	2019 £
Survey income in subsidiary	288,928	259,400
Management fees in subsidiary	733,316	720,988
Miscellaneous trading	816	1,468
	<u>1,023,060</u>	<u>981,856</u>

Any contributions from trading activities are recorded in the unrestricted fund.

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

### 6. INVESTMENT INCOME

	2020 £	2019 £
Rent receivable	20,672	20,300
Interest receivable	5,401	3,062
	<u>26,073</u>	<u>23,362</u>

All investment income is recorded in the unrestricted fund.

### 7. EXPENDITURE ON RAISING FUNDS

		Fundraising Grants & Donations £	Fundraising Events £	Commercial Trading Activity £	Total 2020 £	Total 2019 £
	Note					
Staff costs	15	24,080	44,977	390,369	459,426	456,252
Direct costs	10	32,475	16,092	59,286	107,853	86,041
Depreciation	11	3,227	3,226	1,111	7,564	10,506
Support costs	11	16,110	16,110	30,427	62,647	128,428
		<u>75,892</u>	<u>80,405</u>	<u>481,193</u>	<u>637,490</u>	<u>681,227</u>
Attributable to:						
Unrestricted funds		75,892	80,405	481,193	637,490	681,227
Restricted funds		-	-	-	-	-
		<u>75,892</u>	<u>80,405</u>	<u>481,193</u>	<u>637,490</u>	<u>681,227</u>

### EXPENDITURE ON RAISING FUNDS – 2019 COMPARATIVES

		Fundraising Grants & Donations £	Fundraising Events £	Commercial Trading Activity £	Total 2019 £
	Note				
Staff costs	15	27,113	33,414	395,725	456,252
Direct costs	10	14,754	19,672	51,615	86,041
Depreciation	11	3,803	3,803	2,900	10,506
Support costs	11	17,893	17,893	92,642	128,428
		<u>63,563</u>	<u>74,782</u>	<u>542,882</u>	<u>681,227</u>
Attributable to:					
Unrestricted funds		63,563	74,782	542,882	681,227
Restricted funds		-	-	-	-
		<u>63,563</u>	<u>74,782</u>	<u>542,882</u>	<u>681,227</u>

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

**NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED**  
**for the Year Ended 31 December 2020**

**8. EXPENDITURE ON CHARITABLE ACTIVITIES**

	Note	Advocacy & Members Events £	Awareness Raising £	Commercial Trading Activity Patient Support	Total 2020 £	Total 2019 £
Staff costs	15	296,353	83,099	167,301	546,753	423,187
Direct costs	10	85,733	12,383	-	98,116	235,070
Research grants	12	9,400	-	-	9,400	-
Depreciation	11	16,139	4,841	-	20,980	24,719
Support costs	11	80,546	24,163	-	104,709	116,302
		<u>488,171</u>	<u>124,486</u>	<u>167,301</u>	<u>779,958</u>	<u>799,278</u>
Attributable to:						
Unrestricted funds		12,297	124,486	167,301	304,084	353,313
Restricted funds		475,874	-	-	475,874	445,965
		<u>488,171</u>	<u>124,486</u>	<u>167,301</u>	<u>779,958</u>	<u>799,278</u>

**EXPENDITURE ON CHARITABLE ACTIVITIES – 2019 COMPARATIVES**

	Note	Advocacy & Members Events £	Awareness Raising £	Total 2019 £
Staff costs	15	391,968	31,219	423,187
Direct costs	10	220,316	14,754	235,070
Depreciation	11	19,014	5,705	24,719
Support costs	11	89,463	26,839	116,302
		<u>720,761</u>	<u>78,517</u>	<u>799,278</u>
Attributable to:				
Unrestricted funds		445,965	78,517	353,313
Restricted funds		274,796	-	445,965
		<u>720,761</u>	<u>78,517</u>	<u>799,278</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

### 9. OTHER EXPENDITURE

	Note	Management & Governance 2020 £	Total 2020 £	Management & Governance 2019 £	Total 2019 £
Staff costs	15	49,816	49,816	45,008	45,008
Direct costs	10	16,873	16,873	23,087	23,087
Depreciation	11	4,841	4,841	5,705	5,705
Support costs	11	24,164	24,164	26,839	26,839
		<u>95,694</u>	<u>95,694</u>	<u>100,639</u>	<u>100,639</u>
Attributable to:					
Unrestricted funds		95,694	95,694	100,639	100,639
Restricted funds		-	-	-	-
		<u>95,694</u>	<u>95,694</u>	<u>100,639</u>	<u>100,639</u>

### 10. ALLOCATION OF DIRECT COSTS

	Note	Total Funds 2020 £	Total Funds 2019 £
Advocacy travel		3,210	25,157
Conference and expert meetings		6,196	155,999
Support events		59,456	21,987
Communications		12,383	13,557
MPS awareness		-	14,754
Fundraising expenses		16,092	34,425
Donations and tributes in memory		3,208	901
Management & Governance		16,873	23,088
Survey costs		59,286	52,336
LSD collaborative		833	1,994
Grant consultancy costs		32,475	-
Patient welfare gifts		12,830	-
		<u>222,842</u>	<u>344,198</u>
Attributable to raising funds	7	107,853	86,041
Attributable to charitable activities	8	98,116	235,070
Attributable to other costs	9	16,873	23,087
		<u>222,842</u>	<u>344,198</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

### 11. ALLOCATION OF SUPPORT COSTS

	Note	2020 £	2019 £
Recruitment & training costs		10,566	9,524
General office expenses		91,647	104,242
Insurance		11,180	6,235
Subscriptions		432	5,669
Staff welfare		10,081	8,417
Computer expenses and software		32,469	34,980
Professional fees		7,812	8,951
Bank charges		5,887	3,439
Bad debts		42	1,001
Travel and subsistence		485	23,662
Consultancy expenses		13,499	57,758
Auditors remuneration		6,900	7,690
Depreciation		33,385	40,930
Loss on disposal of asset		520	-
		<u>224,905</u>	<u>312,499</u>
Attributable to raising funds	7	70,211	138,934
Attributable to charitable activities	8	125,689	141,021
Attributable to other costs	9	29,005	32,544
		<u>224,905</u>	<u>312,499</u>

### 12. GRANTS PAYABLE

	2020 £	2019 £
Grants and donations	<u>9,400</u>	<u>-</u>
<b>Grants payable to institutions</b>		
	2020 £	2019 £
Salford Royal NHS Foundation Trust	<u>9,400</u>	<u>-</u>

Grants have been awarded for research into the use of a digital microfluidics platform for the rapid assessment of lysosomal enzyme activity and research into how hydrotherapy can help alleviate pain and improve mobility in patients with MPS conditions. Grants payable costs have all been attributed to charitable activity expenditure.

### 13. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2020 £	2019 £
Auditors' remuneration	6,900	7,500
Depreciation	<u>33,385</u>	<u>40,930</u>

## SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

### NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

#### 14. TRUSTEES' REMUNERATION AND BENEFITS

No trustee or related person received any remuneration from the Society in respect of services as an employee of the entity.

All trustees are reimbursed for their expenses or expenses are paid for by the charity on behalf of trustees, which are necessarily incurred in attending management committee meetings and in performing their duties as trustees. The Chief Executive Officer of the Society approves the reimbursement of such expenses. In 2020 these totalled £2,044 (2019: £5,300) for all trustees.

#### 15. STAFF COSTS

	Group		Charity	
	2020	2019	2020	2019
	£	£	£	£
Wages and salaries	924,436	817,477	439,017	468,536
Social security costs	88,881	76,586	38,114	41,697
Other pension costs	42,677	30,384	21,193	18,488
	<u>1,055,994</u>	<u>924,447</u>	<u>498,324</u>	<u>528,721</u>

The allocation of pension costs between funds follows the allocation of the associated employee remuneration.

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

	Group		Charity	
	2020	2019	2020	2019
	£	£	£	£
Director	2	2	1	1
Administration	3	3	3	3
Advice, information & support	14	15	14	15
Commercial trading operation	11	9	-	-
	<u>30</u>	<u>29</u>	<u>18</u>	<u>19</u>

The number of higher paid employees (excluding employer pension costs) was as follows:

	Group		Charity	
	2020	2019	2020	2019
	£	£	£	£
In the band £80,001 - £90,000	-	1	-	1
In the band £90,001 - £100,000	1	-	1	-
In the band £120,001 - £130,000	1	-	-	-
	<u>2</u>	<u>1</u>	<u>1</u>	<u>1</u>

The key management personnel of the group, comprise the trustees, the group chief executive officer, the commercial chief executive officer, head of advocacy, head of fundraising and head of finance. The total employee benefits of the key management personnel were £418,876 (2019: £305,849). The highest paid director of the charity had accrued £4,701 (2019: £3,553) in employer pension contributions and the highest paid director of the group had accrued £6,375 (2019: £1,042) in employer pension contributions.

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

**NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED**  
**for the Year Ended 31 December 2020**

**16. 2019 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

	Note	Unrestricted funds £	Restricted funds £	2019 Total funds £	2018 Total funds £
<b>INCOME</b>					
<i><b>Voluntary income:</b></i>					
Donations & legacies	3	180,732	-	180,732	144,477
<i><b>Activities for generating funds:</b></i>					
Charitable activities	4	93,602	419,215	512,817	634,878
Other trading activities	5	981,856	-	981,856	685,685
Investment income	6	23,362	-	23,362	37,613
<b>TOTAL INCOME</b>		<b>1,279,552</b>	<b>419,215</b>	<b>1,698,767</b>	<b>1,502,653</b>
<b>EXPENDITURE</b>					
<i><b>Raising funds:</b></i>					
Fundraising grants & donations	7	63,563	-	63,563	61,628
Fundraising activities		74,782	-	74,782	61,152
Trading activities		542,882	-	542,882	440,093
		<b>681,227</b>	<b>-</b>	<b>681,227</b>	<b>562,873</b>
<i><b>Charitable activities:</b></i>					
Advocacy services & member events	8	274,796	445,965	720,761	604,068
Awareness raising		78,517	-	78,517	31,509
		<b>353,313</b>	<b>445,965</b>	<b>799,278</b>	<b>635,577</b>
<i><b>Other costs</b></i>		<b>100,639</b>	<b>-</b>	<b>100,639</b>	<b>95,727</b>
<b>TOTAL EXPENDITURE</b>		<b>1,135,179</b>	<b>445,965</b>	<b>1,581,144</b>	<b>1,294,177</b>
<b>NET INCOME / (EXPENDITURE)</b>		<b>144,373</b>	<b>(26,750)</b>	<b>117,623</b>	<b>208,476</b>
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		2,221,670	75,420	2,297,090	2,088,614
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>2,366,043</b>	<b>48,670</b>	<b>2,414,713</b>	<b>2,297,090</b>

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

**NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED**  
**for the Year Ended 31 December 2020**

**17. TANGIBLE FIXED ASSETS**

<b>Group</b>	<b>Freehold Land and buildings £</b>	<b>Plant and Equipment £</b>	<b>Totals £</b>
<b>COST</b>			
At 1 January 2019	1,435,389	269,840	1,705,229
Additions	-	-	-
Disposals	-	(212,073)	(212,073)
At 31 December 2020	<u>1,435,389</u>	<u>57,767</u>	<u>1,493,156</u>
<b>DEPRECIATION</b>			
At 1 January 2019	322,160	259,552	581,712
Charge for year	28,709	4,676	33,385
Eliminated on disposal	-	(211,553)	(211,553)
At 31 December 2020	<u>350,869</u>	<u>52,675</u>	<u>403,544</u>
<b>NET BOOK VALUE</b>			
At 31 December 2020	<u>1,084,520</u>	<u>5,092</u>	<u>1,089,612</u>
At 31 December 2019	<u>1,113,229</u>	<u>10,288</u>	<u>1,123,517</u>
<b>Charity</b>	<b>Freehold Land and buildings £</b>	<b>Plant and Equipment £</b>	<b>Totals £</b>
<b>COST</b>			
At 1 January 2019	1,435,389	221,636	1,657,025
Additions	-	-	-
Disposals	-	(172,575)	(172,575)
At 31 December 2020	<u>1,435,389</u>	<u>49,061</u>	<u>1,484,450</u>
<b>DEPRECIATION</b>			
At 1 January 2019	322,160	213,552	535,712
Charge for year	28,709	3,564	32,273
Eliminated on disposal	-	(172,575)	(172,575)
At 31 December 2020	<u>350,869</u>	<u>44,541</u>	<u>395,410</u>
<b>NET BOOK VALUE</b>			
At 31 December 2020	<u>1,084,520</u>	<u>4,520</u>	<u>1,089,040</u>
At 31 December 2019	<u>1,113,229</u>	<u>8,084</u>	<u>1,121,313</u>



# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

### 18. FIXED ASSET INVESTMENTS

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Shares in subsidiary	-	2	-	2
Donated jewellery	6,100	6,100	6,100	6,100
Investments in bank bonds	304,797	304,797	300,000	300,000
	<u>310,897</u>	<u>310,899</u>	<u>306,100</u>	<u>306,102</u>

#### Investment in subsidiaries

Subsidiary	Company No.	Percentage shareholding	Class of shares	No of shares	Total value
MPS Commercial Limited	08621283	100	Ordinary £1	1	£1
Rare Disease Research Partners Limited	12249341	100	Ordinary £1	1	£1
					<u>£2</u>

The wholly owned subsidiaries; MPS Commercial Limited and Rare Disease Research Partners Limited and trading and dormant respectively. Both subsidiaries are incorporated in England and Wales, and have the registered office of MPS House, Repton Place, White Lion Road, Amersham, Buckinghamshire, HP7 9LP. All profits generated by subsidiaries are distributed via Gift Aid to the parent charity under a Deed of Covenant.

	MPS Commercial Limited		Rare Disease Research Partners Limited	
	2020	2019 £	2020 £	2019 £
Fixed assets	572	2,203	-	-
Current assets	1,318,376	1,046,602	1	1
Current liabilities	(1,318,947)	(1,048,804)	-	-
Aggregate share capital and reserves	<u>1</u>	<u>1</u>	<u>1</u>	<u>1</u>
Net income from trading activities	<u>350,042</u>	<u>416,643</u>	<u>-</u>	<u>-</u>

There were no investment assets outside the UK.

#### Donated jewellery

The donated jewellery is stated at the valuation arrived at by DJ Warner Jewellers in 2011. The valuers are independent of the Society. The trustees continue to use this basis of valuation.

#### Investment in bank bonds

The Society for Mucopolysaccharide Diseases reinvested £304,947 in fixed business bonds, which are due to mature within less than one year. Of the £304,947 invested, £200,000 has been allocated to the designated fund - £150,000 for the Research Fund and £50,000 for the Service Development Fund.

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

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Trade debtors	249,503	20	592,495	127
Amounts owed by group undertakings	-	601,667	-	616,642
Other debtors	51,387	2,259	55,446	25,824
Prepayments	6,269	6,269	18,280	14,160
	<u>307,159</u>	<u>610,215</u>	<u>666,221</u>	<u>656,753</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

### 20. CASH AT BANK AND IN HAND

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Cash held in parent charity	1,007,555	1,007,555	429,513	429,513
Cash held in subsidiary	1,019,765	-	422,407	-
	<u>2,027,320</u>	<u>1,007,555</u>	<u>851,560</u>	<u>429,153</u>

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

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Trade creditors	16,282	5,337	76,014	11,392
Other creditors	753,259	48,755	442,307	80,522
Accrued expenses	8,430	6,600	14,364	6,695
	<u>777,971</u>	<u>60,692</u>	<u>532,685</u>	<u>98,609</u>

Included within other creditors is deferred income of £209,653 (2019: £353,853). Deferred income is recognised in MPS Commercial where administration fees for patients are spread accordingly with their associated period. Deferred income in The Society For Mucopolysaccharide Diseases is recognised in respect of grants where the performance agreement runs across multiple periods. All of the deferred income recognised in 2019 has been subsequently recognised as income in 2020.

### 22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	2020 Unrestricted funds £	2020 Restricted funds £	2020 Total Funds £	2019 Unrestricted funds £	2019 Restricted Funds £	2019 Total Funds £
Fixed assets	1,089,613	-	1,089,613	1,123,517	-	1,123,517
Investments	310,897	-	310,897	306,100	-	306,100
Current assets	2,016,428	318,050	2,334,478	1,469,111	48,670	1,517,781
Current liabilities	(777,971)	-	(777,971)	(532,685)	-	(532,685)
	<u>2,638,967</u>	<u>318,050</u>	<u>2,957,017</u>	<u>2,366,043</u>	<u>48,670</u>	<u>2,414,713</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2020

### 23. STATEMENT OF FUNDS

#### Group

	Funds at 1 January 2020	Income	Expenditure	Fund Transfers	Funds at 31 December 2020
<b>Unrestricted funds</b>					
General charitable fund	752,815	1,310,192	(959,614)	(353,393)	750,000
Property fund	1,113,228	-	(28,708)	-	1,084,520
Designated funds					
Research fund	250,000	-	(9,400)	126,697	367,297
Service development fund	150,000	-	(39,546)	126,696	237,150
Building refurbishment fund	100,000	-	-	-	100,000
Christine Lavery memorial fund	-	-	-	100,000	100,000
	500,000	-	(48,946)	353,392	804,447
Total unrestricted funds	2,366,043	1,310,192	(1,037,268)	-	2,638,967
<b>Restricted funds</b>					
MPS restricted fund	31,921	635,877	(475,041)	-	192,757
LSD restricted fund	16,749	-	(833)	-	15,916
Research restricted fund	-	109,377	-	-	109,377
Total restricted funds	48,670	745,254	(475,874)	-	318,050
<b>Total Funds</b>	<b>2,414,713</b>	<b>2,055,446</b>	<b>(1,513,142)</b>	<b>-</b>	<b>2,957,017</b>

#### Charity

	Funds at 1 January 2020	Income	Expenditure	Fund Transfers	Funds at 31 December 2020
<b>Unrestricted funds</b>					
General charitable fund	752,815	661,699	(311,121)	(353,393)	750,000
Property fund	1,113,228	-	(28,708)	-	1,084,520
Designated funds					
Research fund	250,000	-	(9,400)	126,697	367,297
Service development fund	150,000	-	(39,546)	126,696	237,150
Building refurbishment fund	100,000	-	-	-	100,000
Christine Lavery memorial fund	-	-	-	100,000	100,000
	500,000	-	(48,946)	-	804,446
Total unrestricted funds	2,366,043	661,699	(388,775)	-	2,638,967
<b>Restricted funds</b>					
MPS restricted fund	31,921	635,877	(475,041)	-	192,757
LSD restricted fund	16,749	-	(833)	-	15,916
Research restricted fund	-	109,377	-	-	109,377
Total restricted funds	48,670	745,254	(475,874)	-	318,050
<b>Total Funds</b>	<b>2,414,713</b>	<b>1,406,953</b>	<b>(864,649)</b>	<b>-</b>	<b>2,957,017</b>

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

**NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED**  
**for the Year Ended 31 December 2020**

**23. STATEMENT OF FUNDS (CONTINUED)**  
**2019 COMPARITIVES**

**Group**

	<b>Funds at 1 January 2019</b>	<b>Income</b>	<b>Expenditure</b>	<b>Fund Transfers</b>	<b>Funds at 31 December 2019</b>
<b><i>Unrestricted funds</i></b>					
General charitable fund	779,734	1,237,832	(1,064,751)	(200,000)	752,815
Property fund	1,141,936	-	(28,708)	-	1,113,228
Designated funds					
Research fund	100,000	41,720	(41,720)	150,000	250,000
Service development fund	100,000	-	-	50,000	150,000
Building refurbishment fund	100,000	-	-	-	100,000
	<u>300,000</u>	<u>41,720</u>	<u>(41,720)</u>	<u>200,000</u>	<u>500,000</u>
Total unrestricted funds	<u>2,221,670</u>	<u>1,279,552</u>	<u>(1,135,179)</u>	<u>-</u>	<u>2,366,043</u>
<b><i>Restricted funds</i></b>					
MPS restricted fund	56,677	419,215	(443,971)	-	31,922
LSD restricted fund	18,743	-	(1,994)	-	16,749
Total restricted funds	<u>75,420</u>	<u>419,215</u>	<u>(445,965)</u>	<u>-</u>	<u>48,670</u>
<b>Total Funds</b>	<u><b>2,297,090</b></u>	<u><b>1,698,767</b></u>	<u><b>(1,581,144)</b></u>	<u><b>-</b></u>	<u><b>2,414,713</b></u>

**Charity**

	<b>Funds at 1 January 2019</b>	<b>Income</b>	<b>Expenditure</b>	<b>Fund Transfers</b>	<b>Funds at 31 December 2019</b>
<b><i>Unrestricted funds</i></b>					
General charitable fund	779,734	695,588	(522,507)	(200,000)	752,815
Property fund	1,141,936	-	(28,708)	-	1,113,228
Designated funds					
Research fund	100,000	41,720	(41,720)	150,000	250,000
Service development fund	100,000	-	-	50,000	150,000
Building refurbishment fund	100,000	-	-	-	100,000
	<u>300,000</u>	<u>41,720</u>	<u>(41,720)</u>	<u>200,000</u>	<u>500,000</u>
Total unrestricted funds	<u>2,221,670</u>	<u>737,308</u>	<u>(592,935)</u>	<u>-</u>	<u>2,366,043</u>
<b><i>Restricted funds</i></b>					
MPS restricted fund	56,677	419,215	(443,971)	-	31,921
LSD restricted fund	18,743	-	(1,994)	-	16,749
Total restricted funds	<u>75,420</u>	<u>419,215</u>	<u>(445,965)</u>	<u>-</u>	<u>48,670</u>
<b>Total Funds</b>	<u><b>2,297,090</b></u>	<u><b>1,156,523</b></u>	<u><b>(1,038,900)</b></u>	<u><b>-</b></u>	<u><b>2,414,713</b></u>

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED** **for the Year Ended 31 December 2020**

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#### **23. STATEMENT OF FUNDS (CONTINUED)**

##### ***Restricted funds***

MPS restricted fund – to support Disease booklets and Advocacy services.

LSD restricted fund – to support Lysosomal Storage Disease related meetings and conferences.

Research restricted fund – to support MPS research related projects

##### ***Designated funds***

Research fund – to support MPS research related projects.

Service development fund – to develop MPS new service for members.

Building refurbishment fund – to maintenance of MPS House.

Christine Lavery memorial fund – to support Christine Lavery's memorial charitable events

#### **24. EVENTS AFTER THE REPORTING DATE**

At the balance sheet date, the World Health Organization had declared the outbreak of COVID-19, a novel strain of coronavirus, a pandemic. The coronavirus outbreak is disrupting supply chains and affecting production and sales across a range of industries. However, despite COVID-19, the group and charity are fully operational and have considered the potential impact of COVID-19 on their operations, risk management and financial forecasts for the period of one year from the date of signing of the financial statements.

As a result of the assessment, the trustees consider that the group and the charity have adequate resources to continue in operational existence for a period of twelve months from signing of the financial statements.

As a result of the assessment of the events and conditions summarised above and based on information available at the date of approval of the financial statements, the group and charity have concluded that there are no material impacts in relation to the COVID-19 pandemic.

The trustees have confirmed there are no other events after the reporting period that are required to be disclosed.

#### **25. RELATED PARTY DISCLOSURES**

MPS Commercial Limited and Rare Disease Research Partners Limited are 100% owned subsidiaries of The Society for Mucopolysaccharide Diseases.

Included in other debtors within the charitable company is the intercompany balance of £601,667 (2019: £616,642). All the profits of MPS Commercial Limited for the period have been distributed by Gift Aid to the Charity. The profits for the year total £350,042 (2019: £416,643).

Rent and recharges of £20,000 (2019: £16,000) were made by The Society for Mucopolysaccharide Diseases to MPS Commercial Limited.

The Society for Mucopolysaccharide Diseases has provided MPS Commercial Limited with a £200,000 long-term loan (2019: £200,000) on which interest of £4,525 (2019: £5,500) was charged.

During the year the charitable company incurred £39,546 (2019: £nil) in consultancy costs with Harvey Pharma Consulting Ltd, a company in which trustee Mr G Harvey is a director. At 31 December 2020 there was a balance of £nil (2019: £nil) due to the related party.

No donations were received from trustees or related parties.

#### **26. ULTIMATE CONTROLLING PARTY**

The board of trustees controls the charity.