

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES  
REPORT OF THE TRUSTEES AND  
AUDITED CONSOLIDATED FINANCIAL STATEMENTS FOR THE YEAR ENDED  
31 DECEMBER 2019**



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



**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

**CONTENTS OF THE FINANCIAL STATEMENTS**  
**for the Year Ended 31 December 2019**

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# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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### **Trustees & Directors**

|                          |                            |
|--------------------------|----------------------------|
| Judith Mary Evans        |                            |
| Wilma Anne Robins        |                            |
| Bryan Gordon Winchester  |                            |
| Kaur Sukhvinder Bhachu   | Resigned 13 December 2019  |
| Daniella Lisa Vandeppeer | Resigned 31 January 2019   |
| David Maurice Patton     |                            |
| James Henry Garthwaite   |                            |
| Robert Gordon Harvey     | Appointed 15 February 2019 |
| Atul Bhanu Mehta         | Appointed 15 February 2019 |
| Philip John Pearson      | Appointed 15 February 2019 |
| Sarah Burgess            | Appointed 28 June 2019     |

**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

**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**

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**for the Year Ended 31 December 2019**

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The trustees who are also the directors of the charity for the purposes of the Companies Act 2006 present their report with the audited financial statements of the charity for the year ended 31 December 2019. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) applicable to charities preparing their accounts in accordance with the Financial Reporting Standard (FRS 102) (effective 1 January 2015).

#### **INTRODUCTION**

During the last twelve months, The MPS Society has built on the solid foundations that were put in place during a period of transition in 2018. The Society has made great progress under the talented leadership team built by Bob Stevens, Group CEO.

The Group's revised strategy and three year plan was finalised early in the year, informed by extensive research into our members' views. The new strategy was launched at the Family Conference at the Hilton, Coventry in June 2019. This bi-annual conference was the high moment of the year. It brought together families, clinicians, researchers and pharmaceutical company representatives, helping each group to learn from others about the complex conditions that our members live with.

In September 2019, the Society held its first dedicated conference for Fabry disease. This too was extremely well received and reinforced our view that more targeted meetings are potentially of greater value to our members. We also hosted our annual bereaved parent weekend in October and a trip to Lapland UK for families in November 2019.

Within the Society, our communications and fundraising team has been strengthened significantly this year and we launched the Society's new website in September. Our advocacy team, the core of what we do, continued to deliver excellent support for families. Treatments introduced over the last 15 years mean that families' needs are changing as more members are now living into adulthood. In 2020 we are undergoing a comprehensive review of family needs to ensure that the Society continues to offer the most relevant and accessible services.

Overall, the Group made a surplus again during the year 2019. This was driven largely by the rapid growth of MPS Commercial, our wholly owned business which provides services to the rare disease community. During the year, a full-time CEO was appointed to the business and it began trading under the name Rare Disease Research Partners ('RDRP'), giving it greater freedom to expand in the coming years.

This surplus enabled us to make more funds available for service development and research projects. We therefore formed a Clinical and Scientific Advisory Committee last summer to manage a rigorous process for the handling of research grant applications.

The senior leadership team has helped reinforce the Society's reputation internationally as a progressive force within the Lysosomal Storage Disease (LSD) community worldwide. We continue to raise awareness of these rare diseases and campaign for access to new treatments and therapies for all those affected. The Society's work has never been more important as ultra-rare diseases face a particularly challenging climate for the reimbursement of new treatments in the UK. We are watching closely for the impact of any policy changes the new Government brings and for the effects of Brexit on research.

It is easy for members to forget the effort required to deliver the breadth and quality of services that the Society provides. We have never been in a stronger position and I want to thank the entire staff team for all that they are achieving, day in, day out.

*James Garthwaite, Chair of Trustees*

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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#### **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 and existing treatments and 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.

Mucopolidoses 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 an 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**

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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 following ways:

- from point of contact we have provided emotional support, practical advice, information and guidance, signposting to other resources where needed
- we have kept to our commitment to have more face to face contact with our members, seeing a 19% increase in visits since 2018
- holding our annual National Conference in June 2019
- holding the first patient expert meeting for our Fabry community
- 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
- investing in ourselves, undertaking a cross sectional study to inform our future aims and objectives, improving our communication streams and launching our new website
- 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
- As part of our objective to support families impacted by our diseases, we held our annual weekend for bereaved parents in Nottingham and a family day to Lapland UK

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**

### **CONTENTS OF THE FINANCIAL STATEMENTS for the Year Ended 31 December 2019**

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#### **ACHIEVEMENTS AND PERFORMANCE**

The rarity of MPS and related lysosomal conditions means that access to clinical specialists, accurate information, treatment possibilities and links with other individuals and families, can sometimes be limited without our support, guidance and interventions.

The MPS Society's Advocacy and Support services provide a unique, flexible caring service which is not just restricted to individual sufferers but is extended to their families and professionals.

#### **How are we contacted?**

- Families/ individuals make contact with us in their own time and this is often dictated by their personal need, this can include times of crisis, which require an immediate response.
- Sometimes we are contacted before a confirmed diagnosis, shortly after diagnosis or even some years later.
- Referrals can come directly from a family, from specialist centres and from other professionals.

#### **What we do on contact?**

- As soon as we receive a request for support we will make contact with the family/ individual to establish how we can help.
- New members are offered a home visit as a matter of course; this helps to build a rapport, we can share information and face-to-face contact helps to have an open conversation. Families like to know who their support worker is and to have consistency. A home visit is often the starting point of our support.

#### **Tailored support that adapts to an individuals need**

- Our support adapts and changes according to need; throughout the course of a person's life circumstances change and there are inevitable transitions that require careful planning and support.
- Transitions can include formal procedural changes such as in education, health and social care. However, people and families also need support in understanding life changes and progression in their disease.
- We work in partnership with individuals, families, health, social care and educational professionals ensuring that the individual and their needs always remains our main priority and focus.

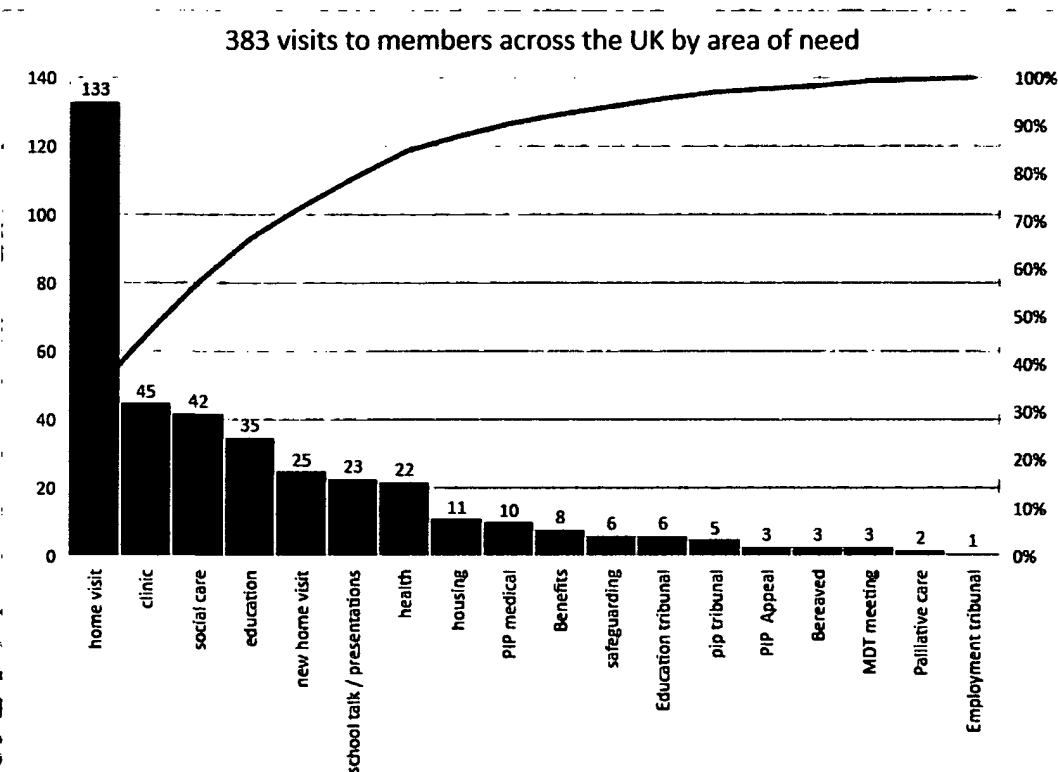
#### **Continuity of support**

- The Advocacy Team are able to develop long standing working relationships with individuals and families.
- This can take the form of continuous involvement or some individuals/families will contact us intermittently.
- Some contact us for one off pieces of work.
- Experience tells us that individuals and families appreciate continuity of support, they like to have a named support worker; therefore, wherever possible allocated support workers maintain their involvement.
- From point of contact the support team provide emotional support, practical advice, information and guidance, signposting to other resources where needed.

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## CONTENTS OF THE FINANCIAL STATEMENTS for the Year Ended 31 December 2019

### Advocacy Outputs for 2019



An overall increase of 19% in the number of visits compared to 2018

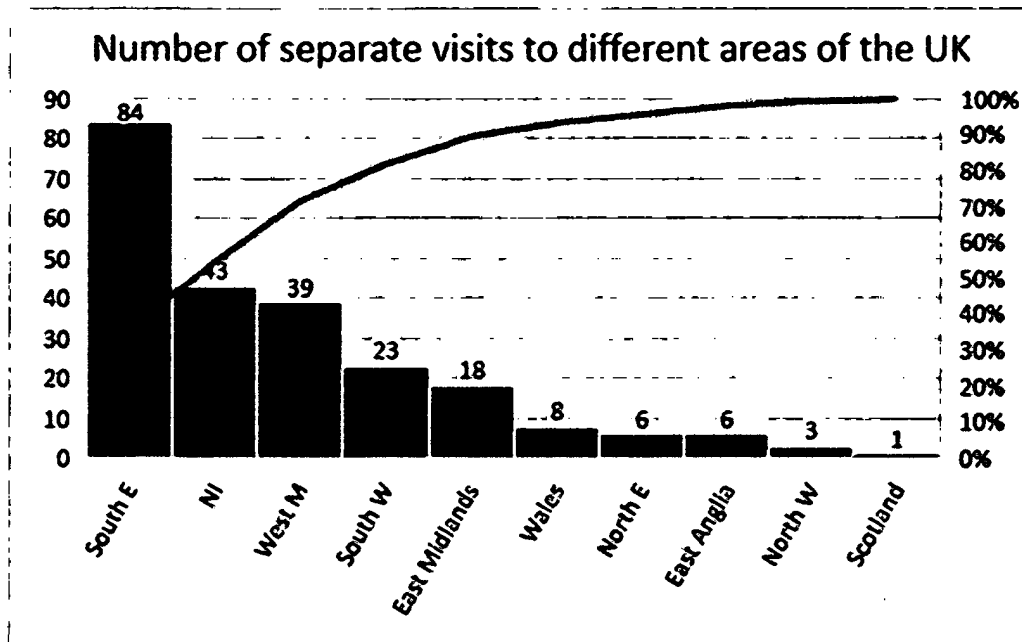
**Other advocacy visit stats (2019 compared to 2018):**

72% increase in number of home visits / new member visits

9% increase in the number of talks / presentations

2% increase in social care support

44% increase in the number of benefit visits

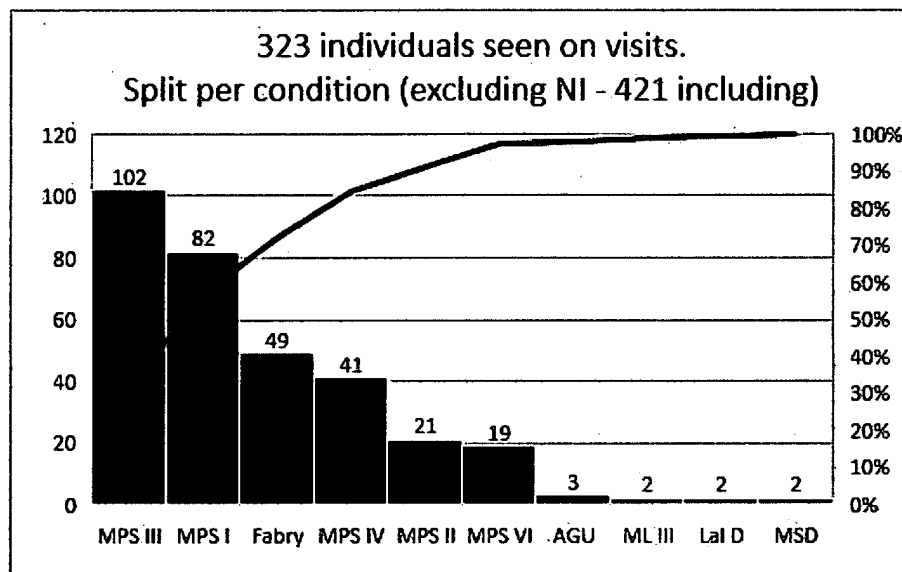




## SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

### CONTENTS OF THE FINANCIAL STATEMENTS for the Year Ended 31 December 2019

#### Advocacy Outputs for 2019



6% increase in the number of members seen compared to 2018

#### Key achievements / highlights for 2019

Due to an increase in support completing benefit forms we have seen a decrease in the number of cases going to tribunal.

The first adult advisory board has been held, and a list of selected topics have been prioritised by the group. The first session focussed on employment with further work planned in this area with expert facilitators. We intend to also cover areas such as mental health, education, independent living, financial information and benefits.

There has been an unprecedented number of education tribunals compared to previous years. For 2019, we supported and in some cases represented six education tribunals. These were mainly in relation to local authorities failing or refusing to provide adequate provisions within an educational setting. In some cases the tribunal was avoided as the support and advocacy representatives were able to negotiate suitable support through mediation processes. All apart from one case were successful; and as a result of further negotiation this young person is now receiving a substantial package of care through continuing healthcare funding.

#### External commitments

The Advocacy and Support team maintained external commitments to support and ensure the patients voice in areas including NICE and EMA and we participated in patient advisory meetings and LSD nurse meetings in order to share ideas on joint projects to improve patient outcomes.

#### Events

A number of events were held throughout the year including: The MPS National conference, our first expert patient meeting on Fabry, a weekend for our bereaved families including planting memorials at the MPS Childhood Wood, Lapland UK, the ongoing Childhood dementia campaign launched its video.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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#### **Fundraising & Communications**

##### **Our supporters**

Last year we raised a total of £238,687 from individual donations, in memory donations, sports challenges, community fundraising and appeals. We are aiming to increase this amount year on year and are pleased with the growth seen in 2019.

##### **Individual donors**

A number of supporters donate to us on a monthly basis and we raised £9,077 from donations in memory. We also received £16,462 in legacy income.

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

A number of supporters chose to raise money for us from doing their own thing in their community such as coffee mornings, bake sales, pub quiz nights, car boot sales and by taking part in our new campaign the Big Blue Bake Off. Together they raised a fantastic £46,774.

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

Our supporters climbed, ran, jumped, cycled and walked throughout 2019 and took part in our new campaigns called Active April and Mini Avengers. Our sports fundraisers collectively raised £37,986. A team of 6 runners took part in the London Marathon, which is the biggest sports event for MPS Society and raised £11,946.

##### **Christmas Campaign**

Last year many individuals supported us by taking part in our new Christmas campaign, the Big Give Christmas Challenge. After setting a target of £10k we went on to raise a total £23k (including gift aid) which will go towards funding our support services in 2020.

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

A key highlight to the year was MPS Awareness Day which was focussed around highlighting the signs and symptoms in MPS conditions so we can encourage an earlier diagnosis for our community. Our posts were seen 66k times on social media, our videos were seen 8k times and we experienced a 94% increase in visitors to our website. The week also raised £8,291. We are grateful to everyone who got involved in the week.

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

The Eveson Charitable Trust, Gosling Foundation, Hobson Charity, Pilkington Charities Fund, Hugh Fraser Foundation and Shauna Gosling Trust are among many grant-making trusts and foundations which have supported the charity in 2019. Grants were also obtained from a number of pharmaceutical companies.

# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

## **CONTENTS OF THE FINANCIAL STATEMENTS for the Year Ended 31 December 2019**

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### **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.

#### **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 two live in Scotland. Geographically, the MPS Society provides a UK wide support and individual advocacy service from our office at MPS House based in Amersham in Buckinghamshire and one support worker based in Belfast. Our 28 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.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **CONTENTS OF THE FINANCIAL STATEMENTS for the Year Ended 31 December 2019**

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

##### **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 unrestricted income by way of donations and fundraising. The fundraising receipts in this reporting period were £93,602 compared with £166,242 in 2018. This shortfall was due to the Christine Lavery appeal held in 2018 but not in 2019. Receipts from general donations and legacies were £180,732 compared with £144,477 in 2018. This year legacies of £16,562 were received whereas £50,800 legacies were received in 2018.

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 2019, MPS Commercial was able to donate £416,643 to the MPS Society. Total group income for the year ending 31 December 2019 was £1,698,767 compared with expenditure of £1,581,144 resulting in a surplus of £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 2019 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 £790,572 (2018: £647,089). The level of free reserves as at 31 December 2019 amounted to £744,730 (2018: £769,372) which amounts to 5.6 months of overall expenditure of the society.

##### **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. In 2018 the trustees recognised that in order to meet these challenges the Society needed to undertake a programme of inward investment: This investment was to:

- **ensure a high quality service to individuals with MPS and related diseases and their families**
- **extend our range and scope of support offered to individuals and families**
- **raise more funds to ensure we can maintain and develop our support for families**
- **increase our public awareness**
- **Update to our infrastructure**

We are happy to report that many of the plans have been actioned and the infrastructure modernisation completed. We have continued to extend our support services offering as a result of the increased demand which has led to a 19% increase in service provision.

The future planning is directly informed by the needs of our community and the changing demands of their lives in the modern world. In 2020 we will begin a new consultation process with all key stakeholders to identify the emerging needs of our community and what a modernised support service from the MPS Society will look like in the future.

# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

## **CONTENTS OF THE FINANCIAL STATEMENTS for the Year Ended 31 December 2019**

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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 Report of the Trustees and the financial statements in accordance with applicable law and Financial Reporting Standards (FRS 102). The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

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
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the Society 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 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.

### **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.

### **AUDITORS**

The auditors, McLintocks (NW) Limited were appointed during the year and will be proposed for re-appointment at the forthcoming Board Meeting. Approved by order of the board of trustees on 27<sup>th</sup> June 2020 and signed on its behalf by:



James Garthwaite, Chair of Trustees  
For the year ended 31 December 2019

## **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 2019 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 2019 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 charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### **Conclusions relating to going concern**

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

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

#### **Other information**

The 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.

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.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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

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

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

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

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

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; 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 set out on page 11, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

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

We have been appointed as auditor under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

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

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.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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

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#### **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**

27<sup>th</sup> June 2020

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

2 Hilliards Court  
Chester Business Park  
Chester  
Cheshire  
CH4 9PX

#### **Notes:**

1. The maintenance and integrity of the MPS Society website 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

## STATEMENT OF CONSOLIDATED FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) for the Year Ended 31 December 2019

|  | Note | Unrestricted<br>funds<br>£ | Restricted<br>funds<br>£ | 2019<br>Total<br>funds<br>£ | 2018<br>Total<br>funds<br>£ |
|--|------|----------------------------|--------------------------|-----------------------------|-----------------------------|
| <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>                   |      |                            |                          |                             |                             |
| 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>                      | 9    | 100,639                    | -                        | 100,639                     | 95,727                      |
| <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>BEFORE TRANSFERS</b>                        |      | <b>144,373</b>             | <b>(26,750)</b>          | <b>117,623</b>              | <b>208,476</b>              |
| Transfers between Funds                        |      | -                          | -                        | -                           | -                           |
| <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>            |

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 2019

|                                     | Notes | 2019<br>Group<br>£ | 2019<br>Charity<br>£ | 2018<br>Group<br>£ | 2018<br>Charity<br>£ |
|-------------------------------------|-------|--------------------|----------------------|--------------------|----------------------|
| <b>FIXED ASSETS</b>                 |       |                    |                      |                    |                      |
| Tangible assets                     | 17    | 1,123,517          | 1,121,313            | 1,155,691          | 1,152,300            |
| Investments                         | 18    | 306,100            | 306,102              | 6,100              | 6,101                |
|                                     |       | <u>1,429,617</u>   | <u>1,427,415</u>     | <u>1,161,791</u>   | <u>1,158,401</u>     |
| <b>CURRENT ASSETS</b>               |       |                    |                      |                    |                      |
| Debtors                             | 19    | 666,221            | 656,754              | 177,791            | 559,217              |
| Cash at bank and in hand            | 20    | 851,560            | 429,153              | 1,185,218          | 598,234              |
|                                     |       | <u>1,517,781</u>   | <u>1,085,907</u>     | <u>1,363,009</u>   | <u>1,157,451</u>     |
| <b>CREDITORS</b>                    |       |                    |                      |                    |                      |
| Amounts falling due within one year | 21    | 532,685            | 98,609               | 227,710            | 18,762               |
| <b>NET CURRENT ASSETS</b>           |       | <u>985,096</u>     | <u>987,298</u>       | <u>1,135,299</u>   | <u>1,138,689</u>     |
| <b>NET ASSETS</b>                   |       | <u>2,414,713</u>   | <u>2,414,713</u>     | <u>2,297,090</u>   | <u>2,297,090</u>     |
| <b>FUNDS</b>                        | 23    |                    |                      |                    |                      |
| Unrestricted Funds:                 |       |                    |                      |                    |                      |
| General charitable funds            |       | 752,815            | 752,815              | 779,734            | 779,734              |
| Designated funds                    |       | 500,000            | 500,000              | 300,000            | 300,000              |
| Property funds                      |       | 1,113,228          | 1,113,228            | 1,141,936          | 1,141,936            |
| Restricted Funds                    |       | <u>48,670</u>      | <u>48,670</u>        | <u>75,420</u>      | <u>75,420</u>        |
| <b>TOTAL FUNDS</b>                  |       | <u>2,414,713</u>   | <u>2,414,713</u>     | <u>2,297,090</u>   | <u>2,297,090</u>     |

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 £117,623 (2018: £208,476).

The consolidated financial statements were approved by the Board of Trustees on 27<sup>th</sup> June 2020 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 2019**

|   |   | 2019<br>£        | 2018<br>£        |
|---|---|------------------|------------------|
| <b>Cash flows from operating activities:</b>                              |   |                  |                  |
| Cash generated from operations  | 1 | (24,902)         | (109,400)        |
| Interest paid   |   | <u>-</u>         | <u>(8,816)</u>   |
| <b>Net cash provided by (used in) operating activities</b>                |   | <u>(24,902)</u>  | <u>(118,216)</u> |
| <b>Cash flows from investing activities:</b>                              |   |                  |                  |
| Purchase of tangible fixed assets   |   | (8,756)          | (7,034)          |
| Investment in bonds   |   | <u>(300,000)</u> | <u>-</u>         |
| <b>Net cash provided by (used in) investing activities</b>                |   | <u>(308,756)</u> | <u>(7,034)</u>   |
| <b>Cash flows financing</b>   |   |                  |                  |
| Amounts repaid on borrowings  |   | <u>-</u>         | <u>(406,184)</u> |
| <b>Net cash provided by (used in) financing</b>                           |   | <u>-</u>         | <u>(406,184)</u> |
| <b>Change in cash and cash equivalents in the reporting period</b>        |   | (333,658)        | (531,434)        |
| <b>Cash and cash equivalents at the beginning of the reporting period</b> | 2 | <u>1,185,218</u> | <u>1,716,652</u> |
| <b>Cash and cash equivalents at the end of the reporting period</b>       | 2 | <u>851,560</u>   | <u>1,185,218</u> |

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED STATEMENT OF CASH FLOWS for the Year Ended 31 December 2019

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

|  | 2019<br>£       | 2018<br>£        |
|--|-----------------|------------------|
| Net income for the reporting period (as per the statement of financial activities) | 117,623         | 208,476          |
| Adjustments for:   |                 |                  |
| Depreciation   | 40,930          | 49,174           |
| Decrease/(increase) in debtors   | (488,430)       | 14,880           |
| Increase/(decrease) in creditors   | <u>304,975</u>  | <u>(381,930)</u> |
| Net cash provided by (used in) operating activities                                | <u>(24,902)</u> | <u>(109,400)</u> |

### 2. ANALYSIS OF CASH AND CASH EQUIVALENTS

|                                 | 2019<br>£      | 2018<br>£        |
|---------------------------------|----------------|------------------|
| Cash in hand                    | 2,472          | 3,530            |
| Bank accounts                   | <u>849,088</u> | <u>1,181,688</u> |
| Total cash and cash equivalents | <u>851,560</u> | <u>1,185,218</u> |

# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

## **NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2019**

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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 trust. 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 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 company has therefore taken advantage of exemptions from the following disclosure requirements for parent company information presented within the consolidated financial statements:

- Section 4 'Statement of Financial Position': Reconciliation of the opening and closing number of shares;
- 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 trading entities are made up to 31 December 2019. The accounts for the dormant company are to be made up to 31 October 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 2019

---

#### 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. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

##### 1.4 Incoming resources

###### *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 receivable are included in the SOFA in the year in which they relate. Grants received relating to future projects are dealt with as grants received in advance and are carried forward as a creditor in the balance sheet at the year end.

###### *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 wholly owned 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 2019**

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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 102.23.4).

##### **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**

Expenditure on fixed assets costing over £800 is capitalised. Expenditure on property and property improvement is depreciated on a straight-line basis over 50 years. Expenditure on computers and office furniture is depreciated on a straight-line basis over 3 to 4 years. Investment assets are included at market value. Investment assets are valued at open market value at the date of donation and subsequently revalued to open market value at least every 5 years.

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

Fixed asset investments are initially measured at cost and subsequently measured at cost less any accumulated impairment losses. The investments are assessed for impairment at each reporting date and any impairment losses or reversals of impairment losses are recognised immediately in net income/(expenditure) for the year.

##### **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.

##### **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 pension schemes are charged to the SOFA in the period to which they relate.

## **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

### **NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2019**

---

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

##### **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 2. 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 2019

### 3. DONATIONS AND LEGACIES

|           | 2019           | 2018           |
|-----------|----------------|----------------|
|           | £              | £              |
| Donations | 164,170        | 93,677         |
| Legacies  | <u>16,562</u>  | <u>50,800</u>  |
|           | <u>180,732</u> | <u>144,477</u> |

### 4. INCOME FROM CHARITABLE ACTIVITIES

|                                 | 2019<br>Unrestricted<br>fund | 2019<br>Restricted<br>fund | 2019<br>Total<br>funds | 2018<br>Total<br>funds |
|---------------------------------|------------------------------|----------------------------|------------------------|------------------------|
|                                 | £                            | £                          | £                      | £                      |
| Research grants                 | -                            | -                          | -                      | 12,747                 |
| Advocacy support grants         | -                            | 236,465                    | 236,465                | 257,552                |
| Conferences and Expert meetings | -                            | 157,750                    | 157,750                | 37,892                 |
| Family support special events   | -                            | 25,000                     | 25,000                 | 66,285                 |
| Christine Lavery Memorial Fund  | -                            | -                          | -                      | 91,336                 |
| Fundraising events              | 91,845                       | -                          | 91,845                 | 166,242                |
| Other income                    | <u>1,757</u>                 | <u>-</u>                   | <u>1,757</u>           | <u>2,824</u>           |
|                                 | <u>93,602</u>                | <u>419,215</u>             | <u>512,817</u>         | <u>634,878</u>         |

In 2018, of the total income from charitable activities, £161,598 was to unrestricted funds and £473,280 was to restricted funds.

### 5. OTHER TRADING ACTIVITIES

|                                      | 2019           | 2018           |
|--------------------------------------|----------------|----------------|
|                                      | £              | £              |
| Survey income in subsidiary          | 259,400        | 198,978        |
| Management fees in subsidiary        | 720,988        | 486,707        |
| Miscellaneous trading in the charity | <u>1,468</u>   | <u>-</u>       |
|                                      | <u>981,856</u> | <u>685,685</u> |

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2019

### 6. INVESTMENT INCOME

|                          | 2019<br>£     | 2018<br>£     |
|--------------------------|---------------|---------------|
| Rents received           | 20,300        | 32,270        |
| Deposit account interest | <u>3,062</u>  | <u>5,343</u>  |
|                          | <u>23,362</u> | <u>37,613</u> |

### 7. EXPENDITURE ON RAISING FUNDS

|               | Note | Fundraising<br>Grants &<br>Donations<br>£ | Fundraising<br>Events<br>£ | Commercial<br>Trading<br>Activity<br>£ | Total<br>2019<br>£ | Total<br>2018<br>£ |
|---------------|------|---|----------------------------|--|--------------------|--------------------|
| Staff costs   |      | 27,113                                    | 33,414                     | 395,725                                | 456,252            | 329,613            |
| Direct costs  | 10   | 14,754                                    | 19,672                     | 51,615                                 | 86,041             | 44,865             |
| Depreciation  |      | 3,803                                     | 3,803                      | 2,900                                  | 10,506             | -                  |
| Support costs | 11   | <u>17,893</u>                             | <u>17,893</u>              | <u>92,642</u>                          | <u>128,428</u>     | <u>188,395</u>     |
|               |      | <u>63,563</u>                             | <u>74,782</u>              | <u>542,882</u>                         | <u>681,227</u>     | <u>562,873</u>     |

### 8. EXPENDITURE ON CHARITABLE ACTIVITIES

|               | Note | Advocacy<br>& Members<br>Events<br>£ | Awareness<br>Raising<br>£ | Total<br>2019<br>£ | Total<br>2018<br>£ |
|---------------|------|--------------------------------------|---------------------------|--------------------|--------------------|
| Staff costs   |      | 391,968                              | 31,219                    | 423,187            | 341,343            |
| Direct costs  | 10   | 220,316                              | 14,754                    | 235,070            | 164,467            |
| Depreciation  |      | 19,014                               | 5,705                     | 24,719             | -                  |
| Support costs | 11   | <u>89,463</u>                        | <u>26,839</u>             | <u>116,302</u>     | <u>129,767</u>     |
|               |      | <u>720,761</u>                       | <u>78,517</u>             | <u>799,278</u>     | <u>635,577</u>     |

### 9. OTHER EXPENDITURE

|               | Note | Management<br>& Governance<br>2019<br>£ | Total<br>2018<br>£ |
|---------------|------|---|--------------------|
| Staff costs   |      | 45,008                                  | 52,473             |
| Direct costs  | 10   | 23,087                                  | -                  |
| Depreciation  |      | 5,705                                   | -                  |
| Support costs | 11   | <u>26,839</u>                           | <u>43,254</u>      |
|               |      | <u>100,639</u>                          | <u>95,727</u>      |

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2019

### 10. ALLOCATION OF DIRECT COSTS

|                                       | Note | 2019<br>Unrestricted<br>expenditure<br>£ | 2019<br>Restricted<br>expenditure<br>£ | 2019<br>Total<br>funds<br>£ | 2018<br>Total<br>funds<br>£ |
|---------------------------------------|------|--|--|-----------------------------|-----------------------------|
| Advocacy travel                       |      | -  | 25,157                                 | 25,157                      | 19,103                      |
| Conference and expert meetings        |      | -  | 155,999                                | 155,999                     | 34,142                      |
| Support events                        |      | -  | 21,987                                 | 21,987                      | 38,383                      |
| Communications                        |      | -  | 13,557                                 | 13,557                      | 13,957                      |
| Research grants                       | 12   | -  | -                                      | -                           | 20,300                      |
| MPS awareness day                     |      | 14,754                                   | -                                      | 14,754                      | 29,960                      |
| Fundraising expenses                  |      | 34,425                                   | -                                      | 34,425                      | 8,698                       |
| Donations and tributes in memory      |      | -  | 901                                    | 901                         | 2,244                       |
| Management & Governance               |      | 23,088                                   | -                                      | 23,088                      | 4,638                       |
| Survey costs                          |      | 52,336                                   | -                                      | 52,336                      | 37,907                      |
| LSD collaborative                     |      | -  | 1,994                                  | 1,994                       | -                           |
|                                       |      | <u>124,603</u>                           | <u>219,595</u>                         | <u>344,198</u>              | <u>209,332</u>              |
| Attributable to raising funds         | 7    | 86,041                                   | -                                      | 86,041                      | 44,865                      |
| Attributable to charitable activities | 8    | <u>38,562</u>                            | <u>219,595</u>                         | <u>258,157</u>              | <u>164,467</u>              |
|                                       |      | <u>124,603</u>                           | <u>219,595</u>                         | <u>344,198</u>              | <u>209,332</u>              |

In 2018, of the total expenditure for direct costs, £76,565 was to unrestricted funds and £132,767 was to restricted funds. All restricted expenditure in 2018 was attributable to charitable activity expenditure.

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2019

### 11. ALLOCATION OF SUPPORT COSTS

|                                       | Note | 2019<br>£      | 2018<br>£      |
|---------------------------------------|------|----------------|----------------|
| Recruitment & training costs          |      | 19,049         | 13,873         |
| General office expenses               |      | 87,550         | 95,768         |
| Governance                            |      | 6,625          | 6,525          |
| Subscriptions                         |      | 3,694          | 3,759          |
| Staff welfare                         |      | 5,847          | 5,566          |
| Computer expenses and software        |      | 23,593         | 76,014         |
| GDPR and database implementation      |      | -              | 6,710          |
| Professional fees                     |      | 11,437         | 12,219         |
| Bank charges                          |      | 1,975          | 3,063          |
| Bank interest                         |      | -              | 8,816          |
| Bad debts                             |      | 44             | 3,263          |
| Depreciation                          |      | 40,930         | 49,174         |
| Travel and subsistence                |      | 23,636         | 39,568         |
| Consultancy expenses                  |      | 39,709         | 32,136         |
| Commercial meetings                   |      | -              | 262            |
| Auditors remuneration                 |      | 7,500          | 4,700          |
|                                       |      | <u>271,569</u> | <u>361,416</u> |
| Attributable to raising funds         | 7    | 128,428        | 188,395        |
| Attributable to charitable activities | 8    | 125,248        | 173,021        |
| Attributable to other costs           | 9    | 17,893         | -              |
|                                       |      | <u>271,569</u> | <u>361,416</u> |

### 12. GRANTS PAYABLE

|                                       | 2019<br>£ | 2018<br>£     |
|---------------------------------------|-----------|---------------|
| Grants and donations                  | <u>-</u>  | <u>20,300</u> |
| <b>Grants payable to institutions</b> |           |               |
|                                       | 2019<br>£ | 2018<br>£     |
| University of Manchester              | <u>-</u>  | <u>20,300</u> |

### 13. NET INCOME/(EXPENDITURE)

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

|                        | 2019<br>£     | 2018<br>£     |
|------------------------|---------------|---------------|
| Auditors' remuneration | 7,500         | 4,700         |
| Depreciation           | <u>40,930</u> | <u>49,174</u> |

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2019

### 14. TRUSTEES' REMUNERATION AND BENEFITS

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

#### Trustees' expenses

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 2019 these totalled £5,300 (2018: £6,525) for all trustees.

### 15. STAFF COSTS

Staff costs were as follows:

|                       | Group          |                | Charity        |                |
|-----------------------|----------------|----------------|----------------|----------------|
|                       | 2019           | 2018           | 2019           | 2018           |
|                       | £              | £              | £              | £              |
| Wages and salaries    | 817,447        | 649,537        | 468,536        | 432,012        |
| Social security costs | 76,586         | 59,844         | 34,889         | 25,928         |
| Other pension costs   | 30,384         | 17,049         | 11,895         | 11,443         |
|                       | <u>924,447</u> | <u>726,430</u> | <u>528,721</u> | <u>469,383</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   |           |
|-------------------------------|-----------|-----------|-----------|-----------|
|                               | 2019      | 2018      | 2019      | 2018      |
|                               | £         | £         | £         | £         |
| Director                      | 2         | 1         | 1         | 1         |
| Administration                | 3         | 3         | 3         | 3         |
| Advice, information & support | 15        | 14        | 15        | 14        |
| Commercial trading operation  | 9         | 9         | -         | -         |
|                               | <u>29</u> | <u>27</u> | <u>19</u> | <u>18</u> |

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

|                               | Group    |          | Charity  |          |
|-------------------------------|----------|----------|----------|----------|
|                               | 2019     | 2018     | 2019     | 2018     |
|                               | £        | £        | £        | £        |
| In the band £80,001 - £90,000 | <u>1</u> | <u>1</u> | <u>1</u> | <u>1</u> |
|                               | <u>1</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, the head of advocacy, head of fundraising and head of finance. The total employee benefits of the key management personnel were £305,849 (2018: £198,000). The highest paid director had accrued £3,553 (2018: £2,016) in employer pension contributions.

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

**NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED**  
for the Year Ended 31 December 2019

**16. 2018 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

|  |      | Unrestricted<br>funds | Restricted<br>funds | 2018<br>Total<br>funds<br>£ | as restated<br>2017<br>Total<br>funds<br>£ |
|--|------|-----------------------|---------------------|-----------------------------|--|
|  | Note | £                     | £                   |                             |  |
| <b>INCOME</b>                                      |      |                       |                     |                             |  |
| <i><b>Voluntary income:</b></i>                    |      |                       |                     |                             |  |
| Donations & legacies                               | 3    | 144,477               | -                   | 144,477                     | 74,820                                     |
| <i><b>Activities for generating funds:</b></i>     |      |                       |                     |                             |  |
| Charitable activities                              | 4    | 161,598               | 473,280             | 634,878                     | 661,703                                    |
| Other trading activities                           | 5    | 685,685               | -                   | 685,685                     | 547,160                                    |
| Investment income                                  | 6    | 37,613                | -                   | 37,613                      | 51,548                                     |
| <b>TOTAL INCOME</b>                                |      | <u>1,029,373</u>      | <u>473,280</u>      | <u>1,502,653</u>            | <u>1,335,231</u>                           |
| <b>EXPENDITURE</b>                                 |      |                       |                     |                             |  |
| <i><b>Raising funds:</b></i>                       |      |                       |                     |                             |  |
| Fundraising grants & donations                     | 7    | 61,628                | -                   | 61,628                      | 69,200                                     |
| Fundraising activities                             |      | 61,152                | -                   | 61,152                      | 81,686                                     |
| Trading activities                                 |      | 440,093               | -                   | 440,093                     | 332,676                                    |
|  |      | <u>562,873</u>        | <u>-</u>            | <u>562,873</u>              | <u>483,562</u>                             |
| <i><b>Charitable activities:</b></i>               |      |                       |                     |                             |  |
| Advocacy services & member events                  | 8    | 148,966               | 455,102             | 604,068                     | 791,155                                    |
| Awareness raising                                  |      | 31,509                | -                   | 31,509                      | 34,654                                     |
|  |      | <u>180,475</u>        | <u>455,102</u>      | <u>635,577</u>              | <u>825,809</u>                             |
| <i><b>Other costs</b></i>                          |      | 95,727                | -                   | 95,727                      | 91,864                                     |
| <b>TOTAL EXPENDITURE</b>                           |      | <u>839,075</u>        | <u>455,102</u>      | <u>1,294,177</u>            | <u>1,401,235</u>                           |
| <b>NET INCOME / (EXPENDITURE) BEFORE TRANSFERS</b> |      |                       |                     |                             |  |
| Transfers between Funds                            |      | 190,298               | 18,178              | 208,476                     | (66,004)                                   |
|  |      | <u>(5,996)</u>        | <u>5,996</u>        | <u>-</u>                    | <u>-</u>                                   |
| <b>NET INCOME / (EXPENDITURE)</b>                  |      | 184,302               | 24,174              | 208,476                     | (66,004)                                   |
| <b>RECONCILIATION OF FUNDS</b>                     |      |                       |                     |                             |  |
| Total funds brought forward                        |      | 2,037,368             | 51,246              | 2,088,614                   | 2,154,618                                  |
| <b>TOTAL FUNDS CARRIED FORWARD</b>                 |      | <u>2,221,670</u>      | <u>75,420</u>       | <u>2,297,090</u>            | <u>2,088,614</u>                           |

# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

## **NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED** **for the Year Ended 31 December 2019**

### **17. TANGIBLE FIXED ASSETS** **Group**

|                       | Land and<br>buildings<br>£ | Plant and<br>equipment<br>£ | Totals<br>£      |
|-----------------------|----------------------------|-----------------------------|------------------|
| <b>COST</b>           |                            |                             |                  |
| At 1 January 2019     | 1,435,389                  | 261,084                     | 1,696,473        |
| Additions             | -                          | 8,756                       | 8,756            |
| At 31 December 2019   | <u>1,435,389</u>           | <u>269,840</u>              | <u>1,705,229</u> |
| <b>DEPRECIATIONS</b>  |                            |                             |                  |
| At 1 January 2019     | 293,452                    | 247,330                     | 540,782          |
| Charge for year       | <u>28,708</u>              | <u>12,222</u>               | <u>40,930</u>    |
| At 31 December 2019   | <u>322,160</u>             | <u>259,552</u>              | <u>581,712</u>   |
| <b>NET BOOK VALUE</b> |                            |                             |                  |
| At 31 December 2019   | <u>1,113,229</u>           | <u>10,288</u>               | <u>1,123,517</u> |
| At 31 December 2018   | <u>1,141,937</u>           | <u>13,754</u>               | <u>1,155,691</u> |

### **TANGIBLE FIXED ASSETS** **Charity**

|                       | Land and<br>buildings<br>£ | Plant and<br>equipment<br>£ | Totals<br>£      |
|-----------------------|----------------------------|-----------------------------|------------------|
| <b>COST</b>           |                            |                             |                  |
| At 1 January 2019     | 1,435,389                  | 214,592                     | 1,649,981        |
| Additions             | -                          | 7,044                       | 7,044            |
| At 31 December 2019   | <u>1,435,389</u>           | <u>221,636</u>              | <u>1,657,025</u> |
| <b>DEPRECIATION</b>   |                            |                             |                  |
| At 1 January 2019     | 293,452                    | 204,229                     | 497,681          |
| Charge for year       | <u>28,708</u>              | <u>9,322</u>                | <u>38,040</u>    |
| At 31 December 2019   | <u>322,160</u>             | <u>213,551</u>              | <u>535,721</u>   |
| <b>NET BOOK VALUE</b> |                            |                             |                  |
| At 31 December 2019   | <u>1,113,229</u>           | <u>8,085</u>                | <u>1,121,304</u> |
| At 31 December 2018   | <u>1,141,938</u>           | <u>10,362</u>               | <u>1,152,300</u> |

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2019

### 18. FIXED ASSET INVESTMENTS

|                           | 2019<br>Group<br>£ | 2019<br>Charity<br>£ | 2018<br>Group<br>£ | 2018<br>Charity<br>£ |
|---------------------------|--------------------|----------------------|--------------------|----------------------|
| Shares in subsidiary      | -                  | 2                    | -                  | 1                    |
| Donated jewellery         | 6,100              | 6,100                | 6,100              | 6,100                |
| Investments in bank bonds | 300,000            | 300,000              | -                  | -                    |
|                           | <u>306,100</u>     | <u>306,102</u>       | <u>6,100</u>       | <u>6,101</u>         |

#### Investment in subsidiaries

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

The wholly owned subsidiaries; MPS Commercial Limited and Rare Disease Research Partners Limited are 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<br>Commercial<br>Limited | MPS<br>Commercial<br>Limited | Rare<br>Disease<br>Research<br>Partners<br>Limited | Rare<br>Disease<br>Research<br>Partners<br>Limited |
|--------------------------------------|------------------------------|------------------------------|--|--|
|                                      | 2019<br>£                    | 2018<br>£                    | 2019<br>£  | 2018<br>£  |
| Fixed assets                         | 2,203                        | 3,391                        | -  | -  |
| Current assets                       | 1,046,602                    | 665,310                      | 1  | -  |
| Current liabilities                  | (1,048,804)                  | (668,700)                    | -  | -  |
| Aggregate share capital and reserves | <u>1</u>                     | <u>1</u>                     | <u>1</u>   | <u>-</u>   |
| Net income from trading activities   | <u>416,643</u>               | <u>231,788</u>               | <u>-</u>   | <u>-</u>   |

There were no investment assets outside the UK.

#### Investment in bank bonds

Society for Mucopolysaccharide Diseases invested £300,000 in fixed business bonds due to mature within less than one year. Of the £300,000 invested, £200,00 have 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

|                                    | 2019<br>Group<br>£ | 2019<br>Charity<br>£ | 2018<br>Group<br>£ | 2018<br>Charity<br>£ |
|------------------------------------|--------------------|----------------------|--------------------|----------------------|
| Trade debtors                      | 592,495            | 127                  | 77,231             | 531                  |
| Amounts owed by group undertakings | -                  | 616,642              | -                  | 459,750              |
| Other debtors                      | 55,446             | 25,824               | 81,281             | 81,178               |
| Prepayments                        | 18,280             | 14,160               | 19,279             | 17,758               |
|                                    | <u>666,221</u>     | <u>656,753</u>       | <u>177,791</u>     | <u>559,217</u>       |



# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2019

### 20. CASH AT BANK AND IN HAND

|                         | 2019<br>Group<br>£ | 2019<br>Charity<br>£ | 2018<br>Group<br>£ | 2018<br>Charity<br>£ |
|-------------------------|--------------------|----------------------|--------------------|----------------------|
| Free reserves           | 80,482             | 80,482               | 222,814            | 222,814              |
| Designated funds        | 300,000            | 300,000              | 300,000            | 300,000              |
| Restricted funds        | 48,671             | 48,671               | 75,420             | 75,420               |
| Cash held in subsidiary | 422,407            | -                    | 586,984            | -                    |
|                         | <u>851,560</u>     | <u>429,153</u>       | <u>1,185,218</u>   | <u>598,234</u>       |

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

|                  | 2019<br>Group<br>£ | 2019<br>Charity<br>£ | 2018<br>Group<br>£ | 2018<br>Charity<br>£ |
|------------------|--------------------|----------------------|--------------------|----------------------|
| Trade creditors  | 76,014             | 11,392               | 13,136             | 7,969                |
| Other creditors  | 442,307            | 6,695                | 38,589             | 2,742                |
| Accrued expenses | 14,364             | 80,522               | 175,985            | 8,051                |
|                  | <u>532,685</u>     | <u>98,609</u>        | <u>227,710</u>     | <u>18,762</u>        |

Included within other creditors is deferred income of £353,853 (2018: £163,132). 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 2018 has been subsequently recognised as income in 2019.

### 22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

|                     | Unrestricted<br>funds<br>£ | Restricted<br>funds<br>£ | 2019<br>Total<br>£ | 2018<br>Total<br>£ |
|---------------------|----------------------------|--------------------------|--------------------|--------------------|
| Fixed assets        | 1,123,517                  | -                        | 1,123,517          | 1,155,691          |
| Investments         | 306,100                    | -                        | 306,100            | 6,100              |
| Current assets      | 1,469,111                  | 48,670                   | 1,517,781          | 1,363,009          |
| Current liabilities | <u>(532,685)</u>           | <u>-</u>                 | <u>(532,685)</u>   | <u>(227,710)</u>   |
|                     | <u>2,366,043</u>           | <u>48,670</u>            | <u>3,504,713</u>   | <u>2,297,090</u>   |

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2019

### 23. STATEMENT OF FUNDS

#### Group

|                             | Funds<br>as at<br>1 January<br>2019 | Income                  | Expenditure               | Fund<br>Transfers | Funds<br>as at 31<br>December<br>2019 |
|-----------------------------|-------------------------------------|-------------------------|---------------------------|-------------------|---------------------------------------|
| <b>Unrestricted funds</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>Restricted funds</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

|                             | Funds<br>as at<br>1 January<br>2019 | Income                  | Expenditure               | Fund<br>Transfers | Funds<br>as at 31<br>December<br>2019 |
|-----------------------------|-------------------------------------|-------------------------|---------------------------|-------------------|---------------------------------------|
| <b>Unrestricted funds</b>   |                                     |                         |                           |                   |                                       |
| General charitable fund     | 779,734                             | 695,588                 | (522,508)                 | (200,000)         | 752,814                               |
| 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>(592,934)</u>          | <u>-</u>          | <u>2,366,042</u>                      |
| <b>Restricted funds</b>     |                                     |                         |                           |                   |                                       |
| MPS restricted fund         | 56,677                              | 419,215                 | (443,970)                 | -                 | 31,922                                |
| LSD restricted fund         | 18,743                              | -                       | (1,994)                   | -                 | 16,749                                |
| Total restricted funds      | <u>75,420</u>                       | <u>419,215</u>          | <u>(445,964)</u>          | <u>-</u>          | <u>48,671</u>                         |
| <b>Total Funds</b>          | <u><b>2,297,090</b></u>             | <u><b>1,156,523</b></u> | <u><b>(1,038,898)</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 2019**

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

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

MPS restricted fund- To support Disease booklets and Advocacy in Gloucestershire & Merseyside  
LSD restricted fund- To support Lysosomal Storage Disease related meetings and conferences

##### ***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.

#### **24. 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 Charity is the intercompany balance of £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 £416,643 (2018: £231,788).

Rent and recharges of £16,000 (2018: £10,000) were made by MPS Society to MPS Commercial.

MPS Society has provided MPS Commercial with a £200,000 long-term loan (2018: £200,000) on which interest of £5,500 (2018: £4,960) was charged.

No donations received from trustees or related parties.

#### **25. ULTIMATE CONTROLLING PARTY**

The board of trustees controls the charity.