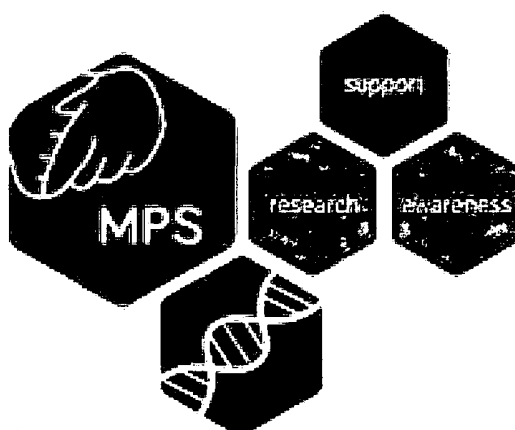
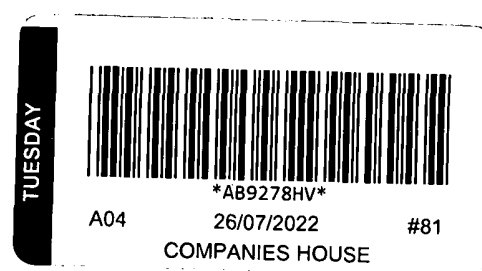


**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES
REPORT OF THE TRUSTEES AND
AUDITED CONSOLIDATED FINANCIAL STATEMENTS FOR THE YEAR ENDED
31 DECEMBER 2021**



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



SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

REFERENCE AND ADMINISTRATION DETAILS **for the Year Ended 31 December 2021**

Trustees & Directors

Katy Brown
Sarah Burgess
Judith Mary Evans
James Henry Garthwaite
Dr Gordon Robert Harvey
Prof Atul Bhanu Mehta
David Maurice Patton
Phillip John Pearson
Wilma Robins
Dr Fiona Stewart
Bryan Gordon Winchester

Registered Company number

7726882 (England and Wales)

Registered Charity number

1143472 / SCO41012

Registered office

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

Company Secretary

Toni Ellerton

Group Chief Executive Officer

Robert Stevens

Auditors

Xeinadin Audit Limited, 2 Hilliards Court, Chester Business Park, Chester, CH4 9PX

Bankers

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

Solicitors

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CHAIRMAN'S STATEMENT

for the Year Ended 31 December 2021

While the World started to open-up again in 2021 for most people, life for many of the individuals and families we support became more complicated. Feelings of isolation and confusion were amplified as a host of additional support needs emerged.

Covid-19 has posed a significant threat to our community and even now, patients feel anxious returning to normal activities. Many feel very isolated as those close to them, including medical professionals, often do not fully understand the complexity of their challenges. Looking after the mental health and wellbeing of our members was therefore the focus of our support during the year.

We responded by providing the widest range of online services we have ever offered to tackle the most difficult aspects of life with a rare disease. These ranged from webinars offering advice from clinicians and other experts, to mindfulness courses and counselling services. To provide the latter, we partnered with Rareminds, a specialist counselling and wellbeing service for the rare disease community. We also partnered with Sibs, a UK charity for brothers and sisters of disabled children and adults, to offer support for our sibling members, many of whom were profoundly affected by the need to shield members of their families during lockdowns.

When times are tough, lifting spirits becomes vitally important so we also organised a range of fun, virtual events and parties for families to meet each other and to bring our community together.

Meanwhile, Rare Disease Research Partners ('RDRP'), our research arm, had to navigate the delay of several clinical trials and a slowdown of other project work from their clients. Fortunately, we were able to redeploy the team's expertise to help play an active role in influencing changes in health services. Specifically, we worked closely with NICE to improve the processes for assessing the needs of the rare disease community, and on the review of several treatments. We also welcomed the publication of the UK Rare Diseases Framework, to which we had contributed extensively at the consultation phase.

Stimulating research remains an integral part of our work and we were therefore pleased to award grant applications for three new research projects during the year in the fields of hydrotherapy, blood testing and the effects of Covid, which are to be paid in 2022.

We could not have done this without our donors who have provided the funds necessary to deliver these important lines of support. We are so grateful for this funding and for the contribution from RDRP.

In 2022 we will continue to work to ensure that all of our community have access to:

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

Once again, despite the practical challenges of the pandemic, the staff team delivered exceptional levels of support to our members. On behalf of all our members, I must record our deep gratitude for their unwavering support - and at a time when the needs of members have never been greater.

James Garthwaite, Chair of Trustees

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

The trustees (who are also the directors of the charity for the purposes of the Companies Act) present their report together with the audited financial statements of the Society for Mucopolysaccharide Diseases (the charity and the group) for the year ended 31 December 2021.

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

OBJECTIVES AND ACTIVITIES

Principal activity

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

Objectives and aims

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

In order to carry out these objectives:

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

To achieve these objectives, we rely on:

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

What are MPS and related lysosomal diseases?

MPS and related diseases are rare diseases affecting one baby born every 8 days in the United Kingdom. We support a group of 25 rare metabolic diseases, referred to as mucopolysaccharide (MPS) diseases or, more commonly, by the name of the doctor who first described the condition, as well as mucopolysaccharide (ML) and other storage diseases. The full list of conditions we support is: MPS I Hurler, MPS I Hurler Scheie, MPS I Scheie, MPS II Hunter, MPS III Sanfilippo, MPS IVA Morquio, MPS VI Maroteaux-Lamy, MPS VII Sly, MPS IX Natowicz, Fabry disease, Aspartylglycosaminuria (AGU), Fucosidosis, Gelebo Physic Dysplasia, GM-1 Gangliosidosis, Lysosomal Acid Lipase Deficiency (LAL D), Alpha-Mannosidosis, Beta-Mannosidosis, MSD Multiple sulphatase deficiency, Metachromatic Leukodystrophy, ML I Neuramidase Deficiency, ML II i-cell disease, ML III Pseudo Hurler Polydystrophy, ML IV, Sialic Acid Storage Disease, Winchester.

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

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

PUBLIC BENEFITS AND ACHIEVEMENTS OF MPS SOCIETY'S WORK PERFORMED

Affected people know where to turn for specialist knowledge, support and advocacy

Covid-19 response

Because of the pandemic, 2021 was another year of uncertainty with lockdowns reintroduced and an accelerated vaccine roll out which raised a number of questions over access, vaccine preference, safety, impact and side effects. To answer these questions the MPS Society facilitated the gathering of Inherited Metabolic Disease (IMD) experts and patient organisations, to address some of these questions, providing practical advice and information. From this webinar a FAQ factsheet was designed.

This further lockdown and uncertainty also led to the development of two additional webinars:

- Gene therapy update for Fabry
- MPS I clinical trial and treatment update

During 2020 we saw a drop in patient engagement in clinical trials, despite centres being open. The aim of these webinars was to inform our communities of developments in these areas and to provide information on the trials available and how to find out more information.

Support and advocacy service

Many of the challenges faced by our membership remained in 2021 as in 2020 with many families continuing to shield and/ or struggling to maintain some essence of normality. With the gradual reopening of daily life came the anxiety associated with returning to school, accessing the community, accepting people back to their homes and returning to work. Local statutory and tertiary services were limited or overwhelmed by demand and so it was important for our team to respond to ensure that the membership was well supported. Key areas of work have included access to services/support, life transitions, reducing isolation, supporting mental health, supporting independence and welfare benefits application and responding wherever possible to the individual needs of each person or family to offer a bespoke service.

Support continued to be offered remotely using virtual means as well as via telephone and email. We aimed to make ourselves as accessible as possible. The team supported the development of resources for both the MPS community and associated professionals, increased their social media presence with the 'we are here' social media campaign and continues to offer weekly social zoom meetings for our young person's group 'Rare Voices'. In addition, the team have worked in conjunction with Project Delivery in the development and implementation of initiatives such as counselling with Rareminds.

Provide services that beneficiaries tell us they need, in a way that suits them

Mental health and wellbeing

A focus for 2021 was providing services to support our communities in managing their mental health and wellbeing. To achieve this we extended our mindfulness courses for patients and parents and carers. We also provided workshops and online videos for all ages on how to understand anxiety as well as techniques to build resilience. Gathering this information together on the mental health and wellbeing hub on our website. Allowed resources to be accessed at all times. Our telephone and online counselling service was launched in the autumn for members over 18, with access to two qualified and experienced counsellors from Rareminds. We also piloted two online workshops with Rareminds for our community, one for male partners, parents and carers and the other for parents and carers. Both workshops explored the emotional and psychological impact of living with a rare disease. They also created opportunities for our community to connect with other members and share their experiences.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

PUBLIC BENEFITS AND ACHIEVEMENTS OF MPS SOCIETY'S WORK PERFORMED (CONTINUED)

Sibling support

Another focus for 2021 was how we support siblings of those with MPS or related diseases. This year we offered online workshops facilitated by Sibs, a UK charity for brothers and sisters of disabled children and adults, to support adult siblings as well as parents and carers. Three workshops were delivered to parents and carers (two of these sessions were 'An Introduction to Supporting Siblings of Disabled Children' and one session was 'How to Deal with Sibling Rivalry'). Three workshops were delivered to adult siblings (two of these sessions were 'An Introduction to Adult Sibling Support' and one session was 'An Introduction to Bereaved Adult Sibling Support'). These interactive workshops enabled members to connect with one other and discuss the challenges of being a sibling or parent. Information was provided about ways to support siblings and their parents as well as where to get more help.

Virtual events

Our online events programmes also continued throughout the year with new offerings. These included three children's parties and a quiz hosted by Rare Voices. More than 20 members had fun at a Comedy Bingo Christmas event which brought together families and their friends. Painting workshops proved to be popular and we held two family sessions and two adult sessions during the year. The events have provided opportunities for families to meet other MPS families online, while taking part in fun activities. The post event feedback has helped with planning subsequent family events to keep our community entertained and enable them to get involved in different activities.

Take an active role in research

Research grants

In 2021 we launched our Clinical Scientific Advisory Committee (CSAC), a small committee, made up of members of the board of trustees and one member of the MPS Society senior leadership team who voluntarily participate in reviewing applications for grants for research projects and recommending them to be funded to the board of trustees as a whole.

CSAC's mission is to scientifically review research proposals to provide an unbiased recommendation to the Board to fund applications which they deem to have scientific merit, be feasible and deliverable and worth the money, in the hopes that the research the MPS Society supports will benefit the patient community in the future. Over the past year, CSAC has specifically focussed on applications that align with the focus of the MPS Society's spotlight on mental health and wellbeing.

CSAC's funding is provided by the MPS Society and is partly made up of some legacy funds which are restricted for the purpose of contributing towards research projects. The Board has awarded three applications this year on the recommendation of CSAC.

Families receive the fastest possible diagnosis

Making recommendations on new initiatives

Despite the uncertainties of Covid-19, 2021 was a year of change and opportunities with the introduction of the UK Rare Diseases Framework, Innovative Medicines Fund and the NHSE Integrated Care Systems. In response to these we actively participated in various working groups including the development of recommendations to better understand how these initiatives may impact the rare disease community. In addition to this we hosted our own "Access to innovation" meeting with industry, other patient organisations and clinicians to review how the Rare Diseases Framework should look in a post-COVID world. Our very own FIND initiative, led by Rare Disease Research Partners (RDRP) was another series of meetings working towards reducing the diagnostic odyssey for patients.

"Thanks very much for all the support that the patient group has given to patients, families and carers alike during this very difficult period and the way they have adapted to the changing times. Your very detailed and specific feedback on the impact of COVID and the NICE process is appreciated"
Recognition from NHS England.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

PUBLIC BENEFITS AND ACHIEVEMENTS OF MPS SOCIETY'S WORK PERFORMED (CONTINUED)

Champion new and existing treatments and therapies

Collaborating with patient services

In 2021 we developed a detailed response to the NICE consultation reviewing their methods and processes. We asked for more equitable access to treatments for rare diseases and a clearer process.

We also worked with NICE on three treatments under the Highly Specialised Technologies (HST) appraisal process. This included our first gene therapy treatment for MLD. Whilst the outcomes were not favourable, the unity of three patient organisations working together to present the patient carer burden of the condition and the quality of life benefits for treated patients was awe-inspiring. We were proud to have our efforts recognised by the NICE committee who:

"commended the patient organisations for their submissions providing detailed feedback from a survey on the effect of treatment on quality of life."

This is a great example of collaboration between three patient organisations and the MPS Society's subsidiary RDRP who specialises in conducting research in rare diseases.

NICE HST process has been a challenge at times. Senior member of MPS and RDRP requested a number of meetings with NICE's CEO and senior personnel to see how we, along with other stakeholders can work with them in reviewing the processes that are currently failing our patients. Reassuringly some of the critical failures have already been actioned by NICE and there is a willingness to being more open and transparent. We look forward to these discussions continuing.

Making it happen by investing in our future

Individual donations

We are very grateful to our supporters who continue to donate to us regularly and received almost £20,000 in regular donations in 2021. We received £20,952 from donations in memory of loved ones, as well as £1,631 from tribute funds and a legacy amounting to £18,299.

Do your own thing

We love hearing about all the creative ways our supporters raise funds for us. In 2021, we raised £10,706 from supporters' own events plus a further £5,261 from Facebook birthday fundraisers.

Events and challenges

Despite the challenges of the pandemic and events being postponed or cancelled, we raised £37,724 from challenge events, other sports events and our very own Active April. The total from the London Marathon was an impressive £15,938 and we raised a further £3,264 from the rescheduled Royal Parks Half Marathon and Great North Run.

Christmas Campaign

We once again entered the Big Give Christmas Challenge and with the help of our pledgers, our Big Give Champion - The Monday Charitable Foundation - and our donors we raised almost £20,000 towards our mental health and wellbeing support services.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

PUBLIC BENEFITS AND ACHIEVEMENTS OF MPS SOCIETY'S WORK PERFORMED (CONTINUED)

MPS Awareness Week

Due to the pandemic our awareness week campaign once again moved online but we were thrilled with the efforts of our members and their families, schools and local communities who supported us. Together they raised £9,000, with one family raising over £5,000, and spread awareness via social media to more than 35,000 people during awareness week.

Trusts and pharmaceutical

We would like to extend a big thank you to our key supporters this year who granted funds towards our services and activities during the continued pandemic, including the National Lottery Community Fund and the Masonic Charitable Foundation.

We have also been very grateful to receive financial contributions from the following pharmaceutical companies towards various aspects of our patient support services: Amicus Therapeutics UK Limited, BioMarin, JCR Pharmaceuticals, Orchard Therapeutics, REGENXBIO Inc, Sangamo Therapeutics Inc, Sanofi, Sigilon Therapeutics Inc, and Takeda UK, who have had no control over the content, activities, or outputs.

Other charitable trusts and foundations who kindly gave donations and grants in 2021 include Zochonis Charitable Trust, Hugh Fraser Foundation, John Cowan Foundation, Clover Trust, Joseph Strong Frazer Trust, John Avins Trust, Borrows Charitable Trust, Bartle Family Charitable Trust, Christopher and Elspeth Thomas Charitable Trust, Costa Coffee Community Fund and Tesco Community Grants.

Public Benefit compliance

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

Fundraising

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

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

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

GOVERNANCE

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 typically 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.

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 CEO and is governed by the Articles of Association.

Wider network

One trustee's first language is Welsh and others live in Scotland. Geographically, the MPS Society provides a UK wide support and individual advocacy service from MPS House based in Amersham in Buckinghamshire. Our 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.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

GOVERNANCE (CONTINUED)

To strengthen governance the Board has established two Sub-Committees, that are chaired by the trustees with permanent representation from members of the executive. As detailed below:

Risk Management Sub-Committee

In 2021 a working group was established to transform the risk management processes within the MPS Society. Identifying best practice from the Charity Commission and using the expert knowledge of selected trustees, a new structure and process was created. Today, the society benefits from a formalised and structured risk management process using insights from the board and expert opinions from the senior staff leadership team. The risk matrix is refreshed on a monthly basis and shared and discussed at each board meeting. The new risk management matrix allows for the simple comprehension of live risks, the archive of old and enables reporting aligned to our strategic goals. Following appropriate governance procedures, the formal Risk Sub-Committee will soon be established, with a clear terms of reference and guiding principles.

We look forward to contributing to the strategic goals of the society while actively working to reduce risk to the business ongoing.

Finance and Audit Sub-Committee

The Finance and Audit Committee undertake a range of duties to support the Executive and the Board to understand the overall financial position of the organisation, deal effectively and proactively with key financial risks and provide the necessary assurances to key stakeholders. This work includes but is not limited to, undertaking a detailed review of the in-year financial position and supporting the management of key risks and opportunities, overseeing the effectiveness of the annual budgeting process to ensure resources are aligned effectively, overseeing the production of the annual report and the associated judgements, reviewing and approving key financial policies, overseeing the effectiveness of the internal control environment and ensuring that appropriate audit arrangements are in place and discharged sufficiently.

The Committee is chaired by a trustee and always has at least one other trustee as a permanent member, in addition to the Group Chief Executive and Head of Finance. The Committee meet 5 times per year and reports on progress and matters for attention at each full Board meeting.

FINANCIAL REVIEW

The MPS Society continues to raise and receive funds through applications to grant giving bodies to support its advocacy service and charitable events, including the salaries of the senior advocacy officer and four advocacy officers, as well as special projects. The Society continues to rely heavily throughout the year on its members and supporters' efforts to raise income by way of donations and fundraising. Income derived from charitable activities (being grants, events and awareness) totalled £334,518 in comparison to £710,104 in 2020. Receipts from donations and legacies were £189,116 compared with £186,832 in 2020. This year legacies of £18,299 were received whereas £109,377 of legacies were received in 2020.

MPS Commercial Limited (trading as Rare Disease Research Partners) 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 2021, MPS Commercial were able to donate £133,218 (2020: £350,042) to the MPS Society. RDRP retains operational independence from the charity with its own Board and CEO. Transactions are undertaken with third parties on a strictly commercial basis and kept wholly separate to dealings with the charity. Potential or actual conflicts arising are regularly reviewed and actively managed in line with the group's conflict of interest policy.

Rare Diseases Research Partners Limited, a wholly owned subsidiary of the MPS Society, continued to be dormant for the entire period

Total group income for the year ending 31 December 2021 was £1,443,246 (2020: £2,055,446) compared with total expenditure of £1,581,251 (2020: £1,513,142) resulting in a deficit of £138,005 (2020: £542,304 surplus).

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2021

RESERVES POLICY

In the year, ending 31 December 2021 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 £790,626 (2020: £756,571). The level of free reserves as at 31 December 2021 amounted to £745,346 (2020: £745,480) which amounts to 5.7 months of overall expenditure of the society.

LOOKING FORWARD

Our focus in 2022 is to deliver services to support the mental health and wellbeing of individuals and families and continue providing the resources that have already proved useful. We will analyse the results of our latest survey on supporting siblings to tailor our support to fit their needs. We will be reviewing our bereavement service and resources and will continue our work and support to young people through our 'Rare Voices' group. In 2022 we will also be celebrating our 40th anniversary year with themed months including a retrospective on the research we have funded in previous years and celebrating those who contribute to our community. We hope that this will also strengthen our MPS Awareness Week campaign in May so we can raise awareness of these conditions with more people.

STATEMENT OF TRUSTEES RESPONSIBILITIES

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

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to:

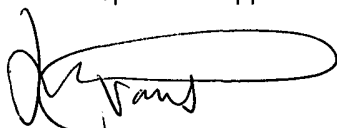
- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity Statement of Recommended Practice (SORP);
- make judgements and estimates that are reasonable and prudent;
state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005. They are also responsible for safeguarding the assets of the charitable company and hence for taking the reasonable steps for the prevention and detection of fraud and other irregularities.

Disclosure of information to auditors

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

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



Judith Evans, Vice-Chair of Trustees
25th June 2022

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

INDEPENDENT AUDITORS' REPORT

TO THE TRUSTEES OF THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Opinion

We have audited the financial statements of The Society For Mucopolysaccharide Diseases (the 'charitable parent company') and its subsidiaries ('the group') for the year ended 31 December 2020 which comprise the group statement of financial activities, the group balance sheet, the charitable company balance sheet, the group statement of cash flows and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

In our opinion the financial statements:

- give a true and fair view of the state of the group's and the charitable company's affairs as at 31 December 2020 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors responsibilities for the audit of the financial statements section of our report. We are independent of the group and the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

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

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

Opinion on other matters prescribed by the Companies Act 2006

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

- the information given in the Report of the Trustees, which includes the directors' report for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

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

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

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees

As explained more fully in the statement of trustees' responsibilities, the trustees, who are also the directors of the charitable company for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor's responsibilities for the audit of the financial statements

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

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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

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

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

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Michael Caputo FCA (Senior Statutory Auditor)
For and on behalf of Xeinadin Audit Limited

25th June 2022

Chartered Accountants
Statutory Auditor

2 Hilliards Court
Chester Business Park
Chester
Cheshire
CH4 9PX

Notes:

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) for the Year Ended 31 December 2021

	Note	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
INCOME					
<i>Voluntary income:</i>					
Donations & legacies	3	207,415	-	207,415	296,209
<i>Activities for generating funds:</i>					
Charitable activities	4	52,163	282,355	334,518	710,104
Other trading activities	5	871,319	-	871,319	1,023,060
Investment income	6	29,994	-	29,994	26,073
TOTAL INCOME		1,160,891	282,355	1,443,246	2,055,446
EXPENDITURE					
<i>Raising funds:</i>					
Fundraising cost of grants & donations	7	71,148	-	71,148	75,892
Fundraising activities		69,045	-	69,045	80,405
Trading activities		457,695	-	457,695	481,193
		597,888	-	597,888	637,490
<i>Charitable activities:</i>					
Advocacy services & member events	8	45,533	425,003	470,536	488,171
Awareness raising		160,353	-	160,353	124,486
Trading activities – Patients support		256,206	-	256,206	167,301
		462,092	425,003	887,095	779,958
<i>Other costs</i>	9	96,268	-	96,268	95,694
TOTAL EXPENDITURE		1,156,248	425,003	1,581,251	1,513,142
NET INCOME/(EXPENDITURE)		4,643	(142,648)	(138,005)	542,304
RECONCILIATION OF FUNDS					
Total funds brought forward		2,638,967	318,050	2,957,017	2,414,713
TOTAL FUNDS CARRIED FORWARD		2,643,610	175,402	2,819,012	2,957,017

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

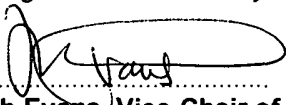
CONSOLIDATED STATEMENT OF FINANCIAL POSITION

At 31 December 2021

	Note	2021 Group £	2021 Charity £	2020 Group £	2020 Charity £
FIXED ASSETS					
Tangible assets	17	1,061,737	1,060,465	1,089,612	1,089,040
Investments	18	315,348	315,350	310,897	310,899
		1,377,085	1,375,815	1,400,509	1,399,939
CURRENT ASSETS					
Debtors	19	315,097	354,679	307,159	610,215
Cash at bank and in hand	20	1,701,427	1,160,157	2,027,320	1,007,555
		2,016,524	1,514,836	2,334,479	1,617,770
CREDITORS					
Amounts falling due within one year	21	574,597	71,639	777,971	60,692
NET CURRENT ASSETS		1,441,927	1,443,197	1,556,508	1,557,078
NET ASSETS		2,819,012	2,819,012	2,957,017	2,957,017
FUNDS	23				
Unrestricted Funds:					
General charitable funds		750,000	750,000	750,000	750,000
Property funds		1,055,811	1,055,811	1,084,520	1,084,520
Designated funds		837,799	837,799	804,447	804,447
		2,643,610	2,643,610	2,638,967	2,638,967
Restricted Funds		175,402	175,402	318,050	318,050
TOTAL FUNDS		2,819,012	2,819,012	2,957,017	2,957,017

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 deficit for the year was £138,005 (2020: surplus £542,304).

The consolidated financial statements were approved by the Board of Trustees on 25th June 2022 and were signed on its behalf by:


 Judith Evans, Vice-Chair of Trustees

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF CASH FLOWS
for the Year Ended 31 December 2021

	Notes	2021 £	2020 £
Cash flows from operating activities:			
Cash generated from operations	1	(315,733)	1,185,958
Interest paid		-	(5,401)
Net cash provided by (used in) operating activities		(315,733)	1,180,557
Cash flows from investing activities:			
Purchase of tangible fixed assets		(5,709)	-
Investment in bonds		(4,451)	(4,797)
Net cash provided by (used in) investing activities		(10,160)	(4,797)
Change in cash and cash equivalents in the reporting period		(325,893)	1,175,760
Cash and cash equivalents at the beginning of the reporting period	2	2,027,320	851,560
Cash and cash equivalents at the end of the reporting period	2	1,701,427	2,027,320

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED STATEMENT OF CASH FLOWS for the Year Ended 31 December 2021

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

	2021 £	2020 £
Net income for the reporting period (as per the statement of financial activities)	(138,005)	542,304
Adjustments for:		
Interest paid	-	5,401
Depreciation	33,584	33,385
Loss on disposal of fixed assets	-	520
Decrease/(increase) in debtors	(7,938)	359,063
Increase/(decrease) in creditors	(203,374)	245,285
Net cash provided by (used in) operating activities	(315,733)	1,185,958

2 ANALYSIS OF CHANGES IN NET FUNDS

	2021 £	2020 £
Cash in hand	1,791	2,289
Bank accounts	1,699,636	2,025,031
Total cash and cash equivalents	1,701,427	2,027,320

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2021

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 group. Monetary amounts in these financial statements are rounded to the nearest £.

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

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

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

1.2 Basis of consolidation

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

All financial statements of subsidiaries are made up to 31 December 2021.

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 2021

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 and group 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

Income is stated after trade discounts and other sales taxes.

Voluntary income

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

Grants receivable

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

Legacies

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

Donations in kind

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

Investment income

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

Income from other trading activities

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

1.5 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources. Grants payable are included in the statement of financial activities 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 2021

1. ACCOUNTING POLICIES (CONTINUED)

1.7 Pass-through costs and reimbursements

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

1.8 Fund accounting

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

1.9 Tangible fixed assets

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

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

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

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

1.10 Fixed asset investments

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

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

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

1.11 Debtors

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

1.12 Cash at bank and in hand

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

1.13 Creditors and provisions

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

1.14 Taxation

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2021

1. ACCOUNTING POLICIES (CONTINUED)

1.15 Pension costs and other post-retirement benefits

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

1.16 Financial Instruments

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

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

Basic financial assets

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

Basic financial liabilities

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

Derecognition of financial liabilities

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

2. LEGAL STATUS

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

3. DONATIONS AND LEGACIES

	2021 Unrestricted fund £	2021 Restricted fund £	2021 Total funds £	2020 Unrestricted fund £	2020 Restricted fund £	2020 Total funds £
Donations	189,116	-	189,116	146,265	40,567	186,832
Legacies	18,299	-	18,299	-	109,377	109,377
	<u>207,415</u>	<u>-</u>	<u>207,415</u>	<u>146,265</u>	<u>149,944</u>	<u>296,209</u>

4. INCOME FROM CHARITABLE ACTIVITIES

	2021 Unrestricted fund £	2021 Restricted fund £	2021 Total funds £	2020 Total funds £
Advocacy support grants	52,163	238,830	290,993	655,004
Conferences and Expert meetings	-	6,025	6,025	33,500
Physiological support	-	32,500	32,500	-
MPS awareness	-	5,000	5,000	-
Family support special events	-	-	-	11,600
Other income	-	-	-	10,000
	<u>52,163</u>	<u>282,355</u>	<u>334,518</u>	<u>710,104</u>

INCOME FROM CHARITABLE ACTIVITIES – 2020 COMPARATIVES

	2020 Unrestricted fund £	2020 Restricted fund £	2020 Total funds £
Advocacy support grants	93,194	561,810	655,004
Conferences and Expert meetings	-	33,500	33,500
Family support special events	11,600	-	11,600
Other income	10,000	-	10,000
	<u>114,794</u>	<u>595,310</u>	<u>710,104</u>

5. OTHER TRADING ACTIVITIES

	2021 £	2020 £
Survey income in subsidiary	240,394	288,928
Management fees in subsidiary	630,428	733,316
Miscellaneous trading	497	816
	<u>871,319</u>	<u>1,023,060</u>

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

6. INVESTMENT INCOME

	2021 £	2020 £
Rent receivable	25,424	20,672
Interest receivable	4,570	5,401
	<u>29,994</u>	<u>26,073</u>

All investment income is recorded in the unrestricted fund.

7. EXPENDITURE ON RAISING FUNDS

		Fundraising Grants & Donations £	Fundraising Events £	Commercial Trading Activity £	Total 2021 £	Total 2020 £
	Note					
Staff costs	15	20,356	37,269	384,310	441,935	459,426
Direct costs	10	33,480	14,464	43,482	91,426	107,853
Depreciation	17	3,273	3,273	1,208	7,754	7,564
Support costs	11	14,039	14,039	28,695	56,773	62,647
		<u>71,148</u>	<u>69,045</u>	<u>457,695</u>	<u>597,888</u>	<u>637,490</u>
Attributable to:						
Unrestricted funds		71,148	69,045	457,695	597,888	637,490
Restricted funds		-	-	-	-	-
		<u>71,148</u>	<u>69,045</u>	<u>457,695</u>	<u>597,888</u>	<u>637,490</u>

EXPENDITURE ON RAISING FUNDS – 2020 COMPARATIVES

		Fundraising Grants & Donations £	Fundraising Events £	Commercial Trading Activity £	Total 2020 £
	Note				
Staff costs	15	24,080	44,977	390,369	459,426
Direct costs	10	32,475	16,092	59,286	107,853
Depreciation	17	3,227	3,226	1,111	7,564
Support costs	11	16,110	16,110	30,427	62,647
		<u>75,892</u>	<u>80,405</u>	<u>481,193</u>	<u>637,490</u>
Attributable to:					
Unrestricted funds		75,892	80,405	481,193	637,490
Restricted funds		-	-	-	-
		<u>75,892</u>	<u>80,405</u>	<u>481,193</u>	<u>637,490</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

8. EXPENDITURE ON CHARITABLE ACTIVITIES

	Note	Advocacy & Members Events £	Awareness Raising £	Commercial Trading Activity Patient Support £	Total 2021 £	Total 2020 £
Staff costs	15	355,318	97,527	256,206	709,051	546,753
Direct costs	10	28,654	36,857	-	65,511	98,116
Research grants	12	-	-	-	-	9,400
Depreciation	17	16,368	4,910	-	21,278	20,980
Support costs	11	70,196	21,059	-	91,255	104,709
		<u>470,536</u>	<u>160,353</u>	<u>256,206</u>	<u>887,095</u>	<u>779,958</u>
Attributable to:						
Unrestricted funds		45,533	160,353	256,206	462,092	304,084
Restricted funds		<u>425,003</u>	<u>-</u>	<u>-</u>	<u>425,003</u>	<u>475,874</u>
		<u>470,536</u>	<u>160,353</u>	<u>256,206</u>	<u>887,095</u>	<u>779,958</u>

EXPENDITURE ON CHARITABLE ACTIVITIES – 2020 COMPARATIVES

	Note	Advocacy & Members Events £	Awareness Raising £	Commercial Trading Activity Patient Support £	Total 2020 £
Staff costs	15	296,353	83,099	167,301	546,753
Direct costs	10	85,733	12,383	-	98,116
Research grants	12	9,400	-	-	9,400
Depreciation	17	16,139	4,841	-	20,980
Support costs	11	80,546	24,163	-	104,709
		<u>488,171</u>	<u>124,486</u>	<u>167,301</u>	<u>779,958</u>
Attributable to:					
Unrestricted funds		12,297	124,486	167,301	304,084
Restricted funds		<u>475,874</u>	<u>-</u>	<u>-</u>	<u>475,874</u>
		<u>488,171</u>	<u>124,486</u>	<u>167,301</u>	<u>779,958</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

9. OTHER EXPENDITURE

	Note	Management & Governance 2021 £	Total 2021 £	Management & Governance 2020 £	Total 2020 £
Staff costs	15	49,504	49,504	49,816	49,816
Direct costs	10	20,794	20,794	16,873	16,873
Depreciation	17	4,552	4,552	4,841	4,841
Support costs	11	21,418	21,418	24,164	24,164
		<u>96,268</u>	<u>96,268</u>	<u>95,694</u>	<u>95,694</u>
Attributable to:					
Unrestricted funds		96,268	96,268	95,694	95,694
Restricted funds		-	-	-	-
		<u>96,268</u>	<u>96,268</u>	<u>95,694</u>	<u>95,694</u>

Any contributions from other expenditure are recorded in the unrestricted fund.

10. ALLOCATION OF DIRECT COSTS

	Note	Total Funds 2021 £	Total Funds 2020 £
Advocacy travel		-	3,210
Conference and expert meetings		1,876	6,196
Support & support events		14,586	59,456
Communications		40,047	12,383
MPS awareness		8,459	-
Fundraising expenses		14,464	16,092
Donations and tributes in memory		224	3,208
Management & Governance		20,794	16,873
Survey costs		43,482	59,286
LSD collaborative		-	833
Grant consultancy costs		33,480	32,475
Patient welfare gifts		319	12,830
		<u>177,731</u>	<u>222,842</u>
Attributable to raising funds	7	91,426	107,853
Attributable to charitable activities	8	65,511	98,116
Attributable to other costs	9	20,794	16,873
		<u>177,731</u>	<u>222,842</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

11. ALLOCATION OF SUPPORT COSTS

	Note	2021 £	2020 £
Recruitment & training costs		18,139	10,566
General office expenses		58,652	91,647
Insurance		19,936	11,180
Subscriptions		437	432
Staff welfare		8,788	10,081
Computer expenses and software		24,784	32,469
Professional fees		12,350	7,812
Bank charges		7,432	5,887
Bad debts		-	42
Travel and subsistence		2,411	485
Consultancy expenses		9,317	13,499
Auditors remuneration		7,200	6,900
Loss on disposal of asset		-	520
		<u>169,446</u>	<u>191,520</u>
Attributable to raising funds	7	56,773	62,647
Attributable to charitable activities	8	91,255	104,709
Attributable to other costs	9	21,418	24,164
		<u>169,446</u>	<u>191,520</u>

12. GRANTS PAYABLE

	2021 £	2020 £
Grants and donations	<u>-</u>	<u>9,400</u>
Grants payable to institutions		
	2021 £	2020 £
Salford Royal NHS Foundation Trust	<u>-</u>	<u>9,400</u>

In 2020, grants were awarded for research into the use of a digital microfluidics platform for the rapid assessment of lysosomal enzyme activity and research into how hydrotherapy can help alleviate pain and improve mobility in patients with MPS conditions. Grants payable costs have all been attributed to charitable activity expenditure.

13. NET INCOME/(EXPENDITURE)

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

	2021 £	2020 £
Auditors' remuneration	6,000	6,900
Auditors' remuneration – non audit services	1,200	-
Depreciation	<u>33,584</u>	<u>33,385</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

14. TRUSTEES' REMUNERATION AND BENEFITS

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

All trustees are reimbursed for their expenses or expenses are paid for by the charity on behalf of trustees, which are necessarily incurred in attending management committee meetings and in performing their duties as trustees. The Chief Executive Officer of the Society approves the reimbursement of such expenses. In 2021 these totalled £1,560 (2020: £2,044) for all trustees.

15. STAFF COSTS

	Group		Charity	
	2021	2020	2021	2020
	£	£	£	£
Wages and salaries	1,051,363	924,436	493,156	439,017
Social security costs	101,771	88,881	44,105	38,114
Other pension costs	47,356	42,677	22,713	21,193
	<u>1,200,490</u>	<u>1,055,994</u>	<u>559,974</u>	<u>498,324</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	
	2021	2020	2021	2020
	£	£	£	£
Chief executives	2	2	1	1
Administration	4	3	4	3
Advice, information & support	12	14	12	14
Commercial trading operation	15	11	-	-
	<u>33</u>	<u>30</u>	<u>17</u>	<u>18</u>

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

	Group		Charity	
	2021	2020	2021	2020
	£	£	£	£
In the band £90,001 - £100,000	1	1	-	1
In the band £120,001 - £130,000	1	1	-	-
	<u>2</u>	<u>2</u>	<u>1</u>	<u>1</u>

The key management personnel of the group, comprise the trustees, the group chief executive officer, the commercial chief executive officer, head of advocacy, head of fundraising and head of finance. The total employee benefits of the key management personnel were £399,366 (2020: £418,876). The highest paid employee of the charity had accrued £4,760 (2020: £4,701) in employer pension contributions and the highest paid employee of the group had accrued £6,439 (2020: £6,375) in employer pension contributions.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

16. 2020 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Note	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
INCOME					
<i>Voluntary income:</i>					
Donations & legacies	3	146,265	149,944	296,209	180,732
<i>Activities for generating funds:</i>					
Charitable activities	4	114,794	595,310	710,104	512,817
Other trading activities	5	1,023,060	-	1,023,060	981,856
Investment income	6	26,073	-	26,073	23,362
TOTAL INCOME		<u>1,310,192</u>	<u>745,254</u>	<u>2,055,446</u>	<u>1,698,767</u>
EXPENDITURE					
<i>Raising funds:</i>					
Fundraising grants & donations	7	63,563	-	63,563	63,563
Fundraising activities		74,782	-	74,782	74,782
Trading activities		542,882	-	542,882	542,882
		<u>681,227</u>	<u>-</u>	<u>681,227</u>	<u>681,227</u>
<i>Charitable activities:</i>					
Advocacy services & member events	8	12,297	475,874	488,171	720,761
Awareness raising		124,486	-	124,486	78,517
Trading activities		167,301	-	167,301	-
		<u>304,084</u>	<u>475,874</u>	<u>779,958</u>	<u>799,278</u>
<i>Other costs</i>		95,694	-	95,694	100,639
TOTAL EXPENDITURE		<u>1,037,268</u>	<u>475,874</u>	<u>1,513,142</u>	<u>1,581,144</u>
NET INCOME / (EXPENDITURE)		272,924	269,380	542,304	117,623
RECONCILIATION OF FUNDS					
Total funds brought forward		2,366,043	48,670	2,414,713	2,229,090
TOTAL FUNDS CARRIED FORWARD		<u>2,638,967</u>	<u>318,050</u>	<u>2,957,017</u>	<u>2,414,713</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

17. TANGIBLE FIXED ASSETS

Group	Freehold Land and buildings £	Plant and Equipment £	Totals £
COST			
At 1 January 2021	1,435,389	57,767	1,493,156
Additions	-	5,709	5,709
Disposals	-	-	-
At 31 December 2021	1,435,389	63,476	1,498,865
DEPRECIATION			
At 1 January 2021	350,869	52,675	403,544
Charge for year	28,708	4,876	33,584
Eliminated on disposal	-	-	-
At 31 December 2021	379,577	57,551	437,128
NET BOOK VALUE			
At 31 December 2021	1,055,812	5,925	1,061,737
At 31 December 2020	1,084,520	5,092	1,089,612
Charity	Freehold Land and buildings £	Plant and Equipment £	Totals £
COST			
At 1 January 2021	1,435,389	49,061	1,484,450
Additions	-	3,801	3,801
Disposals	-	-	-
At 31 December 2021	1,435,389	52,862	1,488,251
DEPRECIATION			
At 1 January 2021	350,869	44,541	395,410
Charge for year	28,708	3,668	32,376
Eliminated on disposal	-	-	-
At 31 December 2021	379,577	48,209	427,786
NET BOOK VALUE			
At 31 December 2021	1,055,812	4,653	1,060,465
At 31 December 2020	1,084,520	4,520	1,089,040

See notes 7, 8 and 9 for the allocation of depreciation.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

18. FIXED ASSET INVESTMENTS

	2021 Group £	2021 Charity £	2020 Group £	2020 Charity £
Shares in subsidiary	-	2	-	2
Donated jewellery	6,100	6,100	6,100	6,100
Investments in bank bonds	309,248	309,248	304,797	304,797
	<u>315,348</u>	<u>315,350</u>	<u>310,897</u>	<u>310,899</u>

Investment in subsidiaries

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

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

	MPS Commercial Limited		Rare Disease Research Partners Limited	
	2021 £	2020 £	2021 £	2020 £
Fixed assets	1,272	572	-	-
Current assets	942,831	1,318,376	1	1
Current liabilities	(944,102)	(1,318,947)	-	-
Aggregate share capital and reserves	<u>1</u>	<u>1</u>	<u>1</u>	<u>1</u>
Net income from trading activities	<u>133,218</u>	<u>350,042</u>	<u>-</u>	<u>-</u>

There were no investment assets outside the UK.

Donated jewellery

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

Investment in bank bonds

The Society for Mucopolysaccharide Diseases reinvested £309,248 in fixed business bonds, which are due to mature within less than one year. Of the £309,248 invested, £200,000 has been allocated to the designated fund - £150,000 for the Research Fund and £50,000 for the Service Development Fund.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

19. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 Group £	2021 Charity £	2020 Group £	2020 Charity £
Trade debtors	260,428	120	249,503	20
Amounts owed by group undertakings	-	333,217	-	601,667
Other debtors	10,257	6,930	51,387	2,259
Prepayments and accrued income	44,412	14,412	6,269	6,269
	<u>315,097</u>	<u>354,679</u>	<u>307,159</u>	<u>610,215</u>

20. CASH AT BANK AND IN HAND

	2021 Group £	2021 Charity £	2020 Group £	2020 Charity £
Cash held in parent charity	1,160,156	1,160,157	1,007,555	1,007,555
Cash held in subsidiary	541,271	-	1,019,765	-
	<u>1,701,427</u>	<u>1,160,157</u>	<u>2,027,320</u>	<u>1,007,555</u>

21. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 Group £	2021 Charity £	2020 Group £	2020 Charity £
Trade creditors	19,087	6,013	16,282	5,337
Other creditors	546,205	58,321	753,259	48,755
Accrued expenses	9,305	7,305	8,430	6,600
	<u>574,597</u>	<u>71,639</u>	<u>777,971</u>	<u>60,692</u>

Included within other creditors is deferred income of £197,730 (2020: £209,953). 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 recorded in 2021 has been subsequently recognised as income in 2022.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	2021 Unrestricted funds £	2021 Restricted funds £	2021 Total Funds £	2020 Unrestricted funds £	2020 Restricted Funds £	2020 Total Funds £
Fixed assets	1,061,737	-	1,061,737	1,089,613	-	1,089,612
Investments	315,348	-	315,348	310,897	-	310,897
Current assets	1,841,122	175,402	2,016,524	2,016,428	318,050	2,334,479
Current liabilities	(574,597)	-	(574,597)	(777,971)	-	(777,971)
	<u>2,643,610</u>	<u>175,402</u>	<u>2,819,012</u>	<u>2,638,967</u>	<u>318,050</u>	<u>2,957,017</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

23. STATEMENT OF FUNDS

Group

	Funds at 1 January 2021	Income	Expenditure	Fund Transfers	Funds at 31 December 2021
Unrestricted funds					
General charitable fund	750,000	1,160,891	(1,127,539)	(33,352)	750,000
Property fund	1,084,520	-	(28,709)	-	1,055,811
Designated funds					
Research fund	367,297	-	-	-	367,297
Service development fund	237,150	-	-	33,352	270,502
Building refurbishment fund	100,000	-	-	-	100,000
Christine Lavery memorial fund	100,000	-	-	-	100,000
	<u>804,447</u>	<u>-</u>	<u>-</u>	<u>33,352</u>	<u>837,799</u>
Total unrestricted funds	<u>2,638,967</u>	<u>1,160,891</u>	<u>(1,156,248)</u>	<u>-</u>	<u>2,643,610</u>
Restricted funds					
MPS restricted fund	192,757	282,355	(425,003)	-	50,109
LSD restricted fund	15,916	-	-	-	15,916
Research restricted fund	109,377	-	-	-	109,377
Total restricted funds	<u>318,050</u>	<u>282,355</u>	<u>(425,003)</u>	<u>-</u>	<u>175,402</u>
Total Funds	<u>2,957,017</u>	<u>1,443,246</u>	<u>(1,581,251)</u>	<u>-</u>	<u>2,819,012</u>

Charity

	Funds at 1 January 2021	Income	Expenditure	Fund Transfers	Funds at 31 December 2021
Unrestricted funds					
General charitable fund	750,000	446,990	(413,638)	(33,352)	750,000
Property fund	1,084,520	-	(28,709)	-	1,055,811
Designated funds					
Research fund	367,297	-	-	-	367,267
Service development fund	237,150	-	-	33,352	270,502
Building refurbishment fund	100,000	-	-	-	100,000
Christine Lavery memorial fund	100,000	-	-	-	100,000
	<u>804,446</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>837,799</u>
Total unrestricted funds	<u>2,638,967</u>	<u>1,160,891</u>	<u>(1,156,248)</u>	<u>-</u>	<u>2,643,610</u>
Restricted funds					
MPS restricted fund	192,757	282,355	(425,003)	-	50,109
LSD restricted fund	15,916	-	-	-	15,916
Research restricted fund	109,377	-	-	-	109,377
Total restricted funds	<u>318,050</u>	<u>282,355</u>	<u>(425,003)</u>	<u>-</u>	<u>175,402</u>
Total Funds	<u>2,957,017</u>	<u>1,443,246</u>	<u>(1,581,251)</u>	<u>-</u>	<u>2,819,012</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2021

23. STATEMENT OF FUNDS (CONTINUED) 2020 COMPARITIVES

Group

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

Charity

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED **for the Year Ended 31 December 2021**

23. STATEMENT OF FUNDS (CONTINUED)

Restricted funds

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

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

Research restricted fund – to support MPS research related projects.

Designated funds

Research fund – to support MPS research related projects.

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

Building refurbishment fund – for the maintenance of MPS House.

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

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 charitable company is the intercompany balance of £333,217 (2020: £601,667). All the profits of MPS Commercial Limited for the period have been distributed by Gift Aid to the charity, these totalled £133,218 (2020: £350,042).

Rent and recharges of £20,000 (2020: £20,000) were made by The Society for Mucopolysaccharide Diseases to MPS Commercial Limited.

The Society for Mucopolysaccharide Diseases has provided MPS Commercial Limited with a £200,000 long-term loan (2020: £200,000) on which interest of £4,200 (2020: £4,525) was charged.

During the year the charitable company incurred £nil (2020: £39,546) in consultancy costs with Harvey Pharma Consulting Ltd, a company in which trustee Mr G Harvey is a director. At 31 December 2021 there was a balance of £nil (2020: £nil) due to the related party.

During the year donations and pledges of £1,503 (2020: £795) were received from trustees of the charity.

25. ULTIMATE CONTROLLING PARTY

The board of trustees controls the charity.