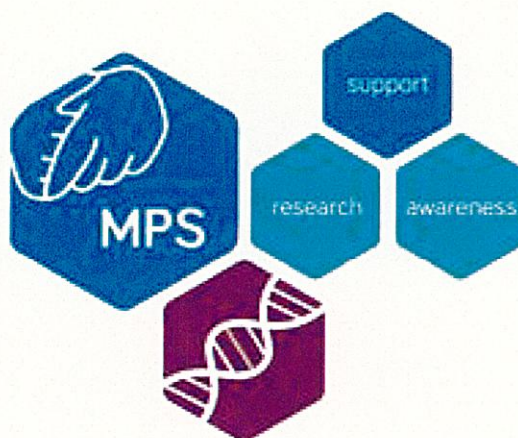


**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES
REPORT OF THE TRUSTEES AND
AUDITED CONSOLIDATED FINANCIAL STATEMENTS FOR THE YEAR ENDED
31 DECEMBER 2022**



**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 2022

Trustees & Directors

Katy Brown
Sarah Burgess
Judith Mary Evans
James Henry Garthwaite
Dr Gordon Robert Harvey (resigned 30.04.22)
Prof Atul Bhanu Mehta (resigned 30.04.22)
Prof Simon James Heales (appointed 22.11.22)
Prof Derralynn Arlene Hughes (appointed 26.11.22)
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 2022

For our 40th year we were able to look back at some amazing work the MPS Society has carried out. Since its inception, the Society has been a pillar for those individuals and families who have felt alone and isolated following a diagnosis of a disease they most likely had never heard of. This fundamental message of community is still in place 40 years later as we make sure the people we support are at the centre of everything we do.

In 2022 we marked the 40th anniversary of the Society with events focusing on particular issues each month. One of the highlights was a reception during MPS Awareness Week, hosted by Jeremy Hunt, MP, at the House of Commons and attended by MPS families, Clinicians, and representatives from Pharmaceutical companies and other long-standing supporters of the Society. Events also included the relaunch and renaming of the Childhood Wood to the Wood of Remembrance and Hope and the launch of the Christine Lavery Memorial Fund which will support a university student to undertake a summer laboratory scheme on an MPS or related disease research project.

Our 40th year coincided with the end of our previous three-year strategy which drew on results from our vision survey of 2018. Our objectives were ambitious and like much of the rare disease landscape, they would change, but on the whole we achieved a lot of what we set out to do.

As we turn our attention to the new three-year strategy, we will continue to put those we support at the centre of everything we do, but now with a proactive approach; rather than purely needs-led, we hope to anticipate those needs and be ready with support.

Alongside a strong focus of understanding and supporting the mental health and wellbeing of our community, we will continue to work on reducing the time to diagnosis through newborn screening and other diagnostic tools that become available. We intend to embed standards across the specialist centres that our community turn to and work with stakeholders to make sure there is equitable access to effective treatments for our community.

With this strong mission and series of priorities I believe the MPS Society will be here for another 40 years, providing support, research and awareness to those who really need it.

Judith Evans, Chair of Trustees
24 June 2023

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2022

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 2022.

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

Our Vision is for all people affected by our diseases to live the lives they want. **Our mission** is to transform lives through specialist knowledge, support and advocacy and research. Our goals are to ensure all our community have access to:

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

In order to carry out these goals we need to operate with effective processes by:

- Achieving a financial performance that is in line with our budget and planning cycle
- Investing in our staff development
- Ensuring good governance and that the organisation is run in line with relevant guidance and

To do this, 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?

Mucopolysaccharide (MPS), Fabry and related lysosomal diseases are a group of rare, genetic diseases that affect the functioning of particular enzymes in the body causing waste materials to accumulate and disrupt the functioning of the body's cells. People 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.

We support people who have one of 27 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, Geleo 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, Gaucher and Farber disease.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2022

PUBLIC BENEFITS AND ACHIEVEMENTS OF MPS SOCIETY'S WORK PERFORMED

Access to Exceptional Support and Advice

Our commitment to mental health and wellbeing

Living with a rare condition can be a challenging and isolating experience. We understand this and have been working to help with any feelings of loneliness our community have. Our Building Connections Project is ongoing but has begun with practical and helpful advice contained in our blog "Top Tips to Combat Loneliness" created using ideas from the Project survey on how to overcome loneliness.

With the help of a grant from the National Lottery Community Fund – Awards for All, we extended the Rareminds therapy course to 16-18 year olds. This is run by qualified psychotherapists who specialise in rare disease patients.

We continue to offer our telephone and online counselling service, which is open to any patient or family members over 16 years old age, as well as our online mindfulness courses thanks in part to generous donations from charitable trusts.

Support events

At the beginning of the year we ran online workshops for parents and carers on how to support siblings in partnership with Sibs, a charity for brothers and sisters of disabled children and adults. We also held some fun online sessions including painting, comedy bingo and quizzes as part of our 40th celebrations.

We were able to hold face-to-face support events for the first time in a while and this was welcomed by our community. The first trip to Legoland was oversubscribed and was followed by other theme park days later in the year.

The bereaved weekend and planting day was combined with the refurbishment and relaunch of the Childhood Wood to the Wood of Remembrance and Hope, which better represents the community we support and those who want a special place to remember a loved one they have lost.

Support services

In 2022 we further expanded our Support and Advocacy Team bringing on different skills, including end of life and bereavement specialists. We provided a wide range of practical and emotional support to our community, having direct contact with more than 1,100 people throughout the year and delivering over 300 in-depth cases of support, for example, with Education, Health and Care (EHC) plans, social care issues and continuing healthcare meetings.

Information

We offered new resources about the diseases we cover including updated booklets and animations. The resources draw on the experience of people affected by our diseases including parents, carers and medical professionals, and are written in plain English and provide accessible information about how best to understand and manage the diseases they cover.

Access to world-class clinical care

Research

As part of our commitment to ensure access to world-class clinical care the Clinical and Scientific Advisory Committee (CSAC) reviewed an encouraging number of research grants in the past year. Including two projects that were delayed due to Covid, we funded six projects and awarded £214,455 in research grants which covered topics such as the link between physical activity and mental health in adults with Fabry disease, and the development of a mathematical model to calculate the risk of worsening airway and lung problems in people with MPS IVA Morquio.

Funding future professionals

In November, we launched the Christine Lavery Memorial Fund on Christine's birthday, to honour her memory and dedication to research and improving the lives of our community. The fund will support a university student to undertake a summer vacation scheme on a research project that will study MPS or related diseases with the aim of encouraging more healthcare professionals to work in, and understand, the area of lysosomal storage diseases.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2022

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

Working with clinical centres

Through our Head of Patient Services and Clinical Liaisons we have worked closely with clinical centres, attending annual clinical meetings and updating them on clinical perspectives as well as delivering patient feedback relating to their experience in attending LSD centres and metabolic appointments. This work also included collaborating with the NHS to put forward recommendations to NHS England for specialist services and reviewing protocols and policy changes.

Newborn Screening

In February 2022, the Department of Health and Social Care (DHSC) published the England Rare Diseases Action Plan containing an important commitment to improving newborn screening (NBS). As members of the Newborn Screen Collaborative we worked in collaboration with the Archangel MLD Trust and other patient organisations to ask for a review of the newborn screening programme, which urgently needs expanding in the UK. As part of the collaborative we also committed to three priorities in 2023: a review of UK NBS policy and processes; a review of current evidence and progress on NBS; and political engagement.

Access to effective treatments

Treatment work

The input of the MPS Society on the approval of new treatments and access to those treatments is vital. We not only convey the patient experience of the condition and treatment but also bring the clinical experience and views via information collected through surveys, questionnaires, focus groups and interviews with patients and clinicians to really understand how the condition impacts patients.

Last year we were involved in the approval of two treatments by National Institute for Health and Care Excellence (NICE) and two with the Scottish Medicines Consortium (SMC).

Breakthrough treatments

Our work as liaison between patients and public body health services brought great results in 2022 when NICE recommend Atidarsagene autotemcel (Libmeldy®) as an option for the treatment of late infantile and early juvenile metachromatic leukodystrophy (MLD). The MPS Society along with two other MLD patient organisations, MLD Support Association UK and ArchAngel MLD Trust, were crucial in delivering information to the committee that informed the decision. NICE commended the patient organisations for their submissions providing detailed feedback from a survey on the effect of Libmeldy® on quality of life. In April 2022 the SMC also approved Atidarsagene autotemcel (Libmeldy®) under its ultra-orphan criteria.

Another welcome piece of news arrived in June when NICE approved Vimizim for treatment in England and Wales. The data that MPS Society and Rare Disease Research Partners (RDRP) collected and submitted was a huge factor in the committee saying yes. NICE stated in a letter "...the patient submissions were very thorough and of the highest standard the committee has seen so far and the committee were not sure they could have asked for more. There was a view that the patient participation outshone the submission and participation from the company for this evaluation."

Operating effective processes

In order to carry out work toward our goals in 2022 we needed to invest in our future.

The MPS Society receives no government funding and so we are really grateful to our supporters without whose generosity we would not be able to continue to provide our vital support to families living with the challenge of MPS conditions.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2022

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

Fundraising and donations

Individual donations - We are very grateful to our supporters who continue to donate to us regularly as we received almost £19,000 in regular donations in 2022. We also received £14,705 from donations in memory of loved ones.

Do your own thing - We love hearing about all the creative ways our supporters raise funds for us. In 2022, we raised just over £18,000 from supporters' own events plus a further £3,595 from Facebook birthday fundraisers and £1,450 from our annual Big Blue Bake Off.

Events and challenges - Despite the continuing challenges of the pandemic and events being postponed or cancelled, we raised £53,840 from challenge events, which includes challenges our supporters take on themselves such as local half marathons, sporty Facebook challenges we run in-house and income from charity places in the London Marathon, Great North Run and London Landmarks Half Marathon.

Christmas Campaign - We once again entered the Big Give Christmas Challenge in December and with the help of our pledgers, our Big Give Champion, The Hospital Saturday Fund and our donors we raised over £28,000 towards funding our 2023 advocacy support services.

MPS Awareness Week - During our annual MPS Awareness Week, we raised almost £8,000 from schools, companies and individuals and we spread awareness via social media reaching more than 52,000 people during the week.

Trusts and pharmaceutical

We would like to extend our sincere thanks to our key supporters this year who granted funds towards our services and activities, including the National Lottery Community Fund and the Gosling Foundation.

Other charitable trusts and foundations who kindly gave donations and grants in 2022 include The Hobson Charity, Geoff and Fiona Squire Foundation, Sisters of the Holy Cross Charitable Trust, National Lottery Community Fund – Awards for All, Zochonis Charitable Trust, Baily Thomas Charitable Fund, Hugh Fraser Foundation, Adint Charitable Trust, Monday Charitable Trust, D'Oyly Carte Charitable Trust, Sandra Charitable Trust, Strangward Trust, Wixamtree Trust, Borrowes Charitable Trust, Joseph Strong Frazer Trust, Clover Trust, Grace Trust, Meikle Foundation, Florence Turner Trust, Oakley Charitable Trust, Bartle Family Charitable Trust, Baddiley Consolidated Charities, Carrington Charitable Trust, Hunter Foundation, John Cowan Foundation, and the Christopher and Elspeth Thomas Charitable Trust.

We were very grateful to receive financial contributions during 2022 from the following pharmaceutical companies towards various aspects of our patient support services and projects: Alexion Pharmaceuticals, Amicus Therapeutics UK Limited, BioMarin, Chiesi, JCR Pharmaceuticals, Orchard Therapeutics, REGENXBIO Inc, Sangamo Therapeutics Inc, and Takeda UK, who have had no input into the content, activities, or outputs.

We also received a grant from MPS Europe towards the costs of an ongoing study.

Our grants and donations from charitable trusts and foundations came to £180,052; funds from pharmaceutical companies came to £229,422; grants from government origins came to £1,283; and grants from other sources came to £29,496; giving a total of £440,253 from these sources.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT) for the Year Ended 31 December 2022

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

Staff

We were pleased with the results of our annual staff survey. All staff agreed or strongly agreed that they understand what the charity wants to achieve with the majority feeling well informed about what is happening in the charity. Most staff (95%) agreed or strongly agreed that they felt like they are making a difference. We continue to invest in our staff, upskilling our Support and Advocacy Team and offering training opportunities as they arise and have embraced a hybrid working approach in 2022 to give our employees the best work-life balance we can.

Governance

In 2022, James Garthwaite stepped down as Chair of Trustees and was replaced by Judith Evans who originally joined the board of trustees in 2000, took a short break in 2016 and returned to the board in 2018. However, she has been part of the MPS Society since 1989 when her daughter was diagnosed with MPS IVA Morquio. Our trustees meet four times a year in person for formal board meetings and take it in turns to attend monthly all-staff meetings. In our staff survey, 91% of MPS Society staff said they have confidence in the trustee board to carry out our charitable mission.

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 2022

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 directors/trustees 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.

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

Risk Sub-Committee

In 2022 a Risk Sub-Committee was formally established, with clear terms of reference and guiding principles. 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.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT)

for the Year Ended 31 December 2022

GOVERNANCE (CONTINUED)

Audit and Finance Sub-Committee

The Audit and Finance 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.

Clinical and Scientific Advisory Sub-Committee (CSAC)

The aim of the CSAC Committee is to ensure that the voices of the patient community, the clinical community and the scientific community are involved in the consideration of research.

The main function are:

- To consider the importance, scientific merit and potential impact of research grant applications made to the MPS Society. When appropriate, external peer review of research grant applications will be sought.
- To provide a recommendation to the MPS Board of Trustees on the funding of research grant applications made to the MPS Society.
- CSAC may also make the MPS Board of Trustees aware of potential future areas of research for support.
- Advise the Board on potential CSAC members.
- Act collectively or individually as source of advice to the MPS Society on clinical or scientific research.

The Board of Trustees will appoint a Chair of CSAC who will be a member of the main MPS Board of Trustees. The subcommittee will appoint a Vice-Chair from the membership of CSAC. Each member will be appointed for a term of 3 years and new members may be appointed at any time.

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 £471,717 in comparison to £334,518 in 2021. Receipts from donations £174,931 compared with £189,116 in 2021. This year legacies of £15,208 were received whereas £18,299 of legacies were received in 2021.

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 2022, MPS Commercial were able to donate £232,465 (2021: £133,218) 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.

Total group income for the year ending 31 December 2022 was £ 1,721,243 (2021: £1,443,246) compared with total expenditure of £2,101,927 (2021: £1,581,251) resulting in a deficit of £289,684 (2021: £138,005 deficit).

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 2022

RESERVES POLICY

In the year, ending 31 December 2022 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 core expenditure equates to £667,547 (2021: £790,626). The level of free reserves as at 31 December 2022 amounted to £742,845 (2021: £745,346) which amounts to 6 months of overall expenditure of the society.

LOOKING FORWARD

Our focus in 2023 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.

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:

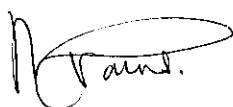
- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity Statement of Recommended Practice (SORP);
- make judgements and estimates that are reasonable and prudent;
state whether applicable UK Accounting Standards have been followed, subject 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, Chair of Trustees
24 June 2023

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 2022 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 2022 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.



**Helen Furlong FCCA (Senior Statutory Auditor)
For and on behalf of Xeinadin Audit Limited**

**Chartered Accountants
Statutory Auditor**

3.7.23

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 2022

| | Note | Unrestricted funds £ | Restricted funds £ | 2022 Total funds £ | 2021 Total funds £ |
|---|------|-------------------------|-----------------------|--------------------------|--------------------------|
| INCOME | | | | | |
| <i>Voluntary income:</i> | | | | | |
| Donations & legacies | 3 | 190,139 | - | 190,139 | 207,415 |
| <i>Activities for generating funds:</i> | | | | | |
| Charitable activities | 4 | 102,297 | 369,420 | 471,717 | 334,518 |
| Other trading activities | 5 | 1,026,165 | - | 1,026,165 | 871,319 |
| Investment income | 6 | 33,222 | - | 33,222 | 29,994 |
| TOTAL INCOME | | 1,351,823 | 369,420 | 1,721,243 | 1,443,246 |
| EXPENDITURE | | | | | |
| <i>Raising funds:</i> | | | | | |
| Fundraising cost of grants & donations | 7 | 72,606 | - | 72,606 | 71,148 |
| Fundraising activities | | 76,649 | - | 76,649 | 69,045 |
| Trading activities | | 505,428 | - | 505,428 | 457,695 |
| | | <u>654,683</u> | <u>-</u> | <u>654,683</u> | <u>597,888</u> |
| <i>Charitable activities:</i> | | | | | |
| Advocacy services & member events | 8 | 515,669 | 302,564 | 818,233 | 470,536 |
| Awareness raising | | 176,418 | - | 176,418 | 160,353 |
| Trading activities – Patients support | | 262,147 | - | 262,147 | 256,206 |
| | | <u>954,234</u> | <u>302,564</u> | <u>1,256,798</u> | <u>887,095</u> |
| <i>Other costs</i> | 9 | 94,800 | 4,646 | 99,446 | 96,268 |
| TOTAL EXPENDITURE | | 1,703,717 | 307,210 | 2,101,927 | 1,581,251 |
| NET INCOME/(EXPENDITURE) | | (351,894) | 62,210 | (289,684) | (138,005) |
| RECONCILIATION OF FUNDS | | | | | |
| Total funds brought forward | | 2,643,610 | 175,402 | 2,819,012 | 2,957,017 |
| TOTAL FUNDS CARRIED FORWARD | | <u>2,291,716</u> | <u>237,612</u> | <u>2,529,328</u> | <u>2,819,012</u> |

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

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

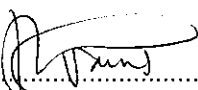
CONSOLIDATED STATEMENT OF FINANCIAL POSITION

At 31 December 2022

| | Note | 2022 Group £ | 2022 Charity £ | 2021 Group £ | 2021 Charity £ |
|-------------------------------------|------|--------------------|----------------------|--------------------|----------------------|
| FIXED ASSETS | | | | | |
| Tangible assets | 17 | 1,034,258 | 1,033,622 | 1,061,737 | 1,060,465 |
| Investments | 18 | 317,126 | 317,128 | 315,348 | 315,350 |
| | | <u>1,351,384</u> | <u>1,350,750</u> | <u>1,377,085</u> | <u>1,375,815</u> |
| CURRENT ASSETS | | | | | |
| Debtors | 19 | 368,552 | 447,601 | 315,097 | 354,679 |
| Cash at bank and in hand | 20 | 1,287,900 | 793,648 | 1,701,427 | 1,160,157 |
| | | <u>1,656,452</u> | <u>1,241,249</u> | <u>2,016,524</u> | <u>1,514,836</u> |
| CREDITORS | | | | | |
| Amounts falling due within one year | 21 | 478,508 | 62,671 | 574,597 | 71,639 |
| | | <u>1,177,944</u> | <u>1,178,578</u> | <u>1,441,927</u> | <u>1,443,197</u> |
| NET CURRENT ASSETS | | | | | |
| | | <u>2,529,328</u> | <u>2,529,328</u> | <u>2,819,012</u> | <u>2,819,012</u> |
| NET ASSETS | | | | | |
| FUNDS | | | | | |
| | 23 | | | | |
| Unrestricted Funds: | | | | | |
| General charitable funds | | 750,000 | 750,000 | 750,000 | 750,000 |
| Property funds | | 1,027,103 | 1,027,103 | 1,055,811 | 1,055,811 |
| Designated funds | | 514,612 | 514,612 | 837,799 | 837,799 |
| | | <u>2,291,715</u> | <u>2,291,715</u> | <u>2,638,967</u> | <u>2,638,967</u> |
| Restricted Funds | | 237,613 | 237,613 | 175,402 | 175,402 |
| TOTAL FUNDS | | | | | |
| | | <u>2,529,328</u> | <u>2,529,328</u> | <u>2,819,012</u> | <u>2,819,012</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 deficit for the year was £289,684 (2021: surplus £138,005).

The consolidated financial statements were approved by the Board of Trustees on 24 June 2023 and were signed on its behalf by:



Judith Evans, Chair of Trustees

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF CASH FLOWS
for the Year Ended 31 December 2022

| | Notes | 2022 £ | 2021 £ |
|---|-------|------------------|------------------|
| Cash flows from operating activities: | | | |
| Cash generated from operations | 1 | (405,087) | (315,733) |
| Interest paid | | - | - |
| Net cash provided by (used in) operating activities | | (405,087) | (315,733) |
| Cash flows from investing activities: | | | |
| Purchase of tangible fixed assets | | (6,662) | (5,709) |
| Investment in bonds | | (1,778) | (4,451) |
| Net cash provided by (used in) investing activities | | (8,440) | (10,160) |
| Change in cash and cash equivalents in the reporting period | | (413,527) | (325,893) |
| Cash and cash equivalents at the beginning of the reporting period | 2 | 1,701,427 | 2,027,320 |
| Cash and cash equivalents at the end of the reporting period | 2 | 1,287,900 | 1,701,427 |

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED STATEMENT OF CASH FLOWS
for the Year Ended 31 December 2022

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

| | 2022 | 2021 |
|---|------------------|------------------|
| | £ | £ |
| Net income for the reporting period (as per the statement of financial activities) | (289,684) | (138,005) |
| Adjustments for: | | |
| Interest paid | - | - |
| Depreciation | 34,141 | 33,584 |
| Loss on disposal of fixed assets | - | - |
| Decrease/(increase) in debtors | (53,455) | (7,938) |
| Increase/(decrease) in creditors | (96,089) | (203,374) |
| | <hr/> | <hr/> |
| Net cash provided by (used in) operating activities | (405,087) | (315,733) |
| | <hr/> <hr/> | <hr/> <hr/> |

2 ANALYSIS OF CHANGES IN NET FUNDS

| | 2022 | 2021 |
|--|------------------|------------------|
| | £ | £ |
| Cash in hand | 1,594 | 1,791 |
| Bank accounts | 1,286,306 | 1,699,636 |
| | <hr/> | <hr/> |
| Total cash and cash equivalents | 1,287,900 | 1,701,427 |
| | <hr/> <hr/> | <hr/> <hr/> |

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2022

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 2022.

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 2022

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 2022

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 2022

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 2022

3. DONATIONS AND LEGACIES

| | 2022 Unrestricted fund £ | 2022 Restricted fund £ | 2022 Total funds £ | 2021 Unrestricted fund £ | 2021 Restricted fund £ | 2021 Total funds £ |
|-----------|-----------------------------------|---------------------------------|-----------------------------|-----------------------------------|---------------------------------|-----------------------------|
| Donations | 174,931 | - | 174,931 | 189,116 | - | 189,116 |
| Legacies | 15,208 | - | 15,208 | 18,299 | - | 18,299 |
| | <u>190,139</u> | <u>-</u> | <u>190,139</u> | <u>207,415</u> | <u>-</u> | <u>207,415</u> |

4. INCOME FROM CHARITABLE ACTIVITIES

| | 2022 Unrestricted fund £ | 2022 Restricted fund £ | 2022 Total funds £ | 2021 Total funds £ |
|---------------------------------|-----------------------------------|---------------------------------|-----------------------------|-----------------------------|
| Advocacy support grants | 99,797 | 277,170 | 376,967 | 290,993 |
| Conferences and Expert meetings | - | - | - | 6,025 |
| Physiological support | - | 33,500 | 33,500 | 32,500 |
| MPS awareness | - | 25,000 | 25,000 | 5,000 |
| Family support special events | - | 33,750 | 33,750 | - |
| Other income | 2,500 | - | 2,500 | - |
| | <u>102,297</u> | <u>369,420</u> | <u>471,717</u> | <u>334,518</u> |

INCOME FROM CHARITABLE ACTIVITIES – 2021 COMPARATIVES

| | 2021 Unrestricted fund £ | 2021 Restricted fund £ | 2021 Total funds £ |
|---------------------------------|-----------------------------------|---------------------------------|-----------------------------|
| Advocacy support grants | 52,163 | 238,830 | 290,993 |
| Conferences and Expert meetings | - | 6,025 | 6,025 |
| Physiological support | - | 32,500 | 32,500 |
| MPS awareness | - | 5,000 | 5,000 |
| | <u>52,163</u> | <u>282,355</u> | <u>334,518</u> |

5. OTHER TRADING ACTIVITIES

| | 2022 £ | 2021 £ |
|-------------------------------|------------------|----------------|
| Survey income in subsidiary | 456,623 | 240,394 |
| Management fees in subsidiary | 568,898 | 630,428 |
| Miscellaneous trading | 644 | 497 |
| | <u>1,026,165</u> | <u>871,319</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 2022

6. INVESTMENT INCOME

| | 2022 £ | 2021 £ |
|---------------------|---------------|---------------|
| Rent receivable | 29,951 | 25,424 |
| Interest receivable | 3,271 | 4,570 |
| | <u>33,222</u> | <u>29,994</u> |

All investment income is recorded in the unrestricted fund.

7. EXPENDITURE ON RAISING FUNDS

| | | Fundraising Grants & Donations £ | Fundraising Events £ | Commercial Trading Activity £ | Total 2022 £ | Total 2021 £ |
|--------------------|------|---|----------------------------|--|--------------------|--------------------|
| | Note | | | | | |
| Staff costs | 15 | 22,015 | 39,066 | 393,220 | 454,301 | 441,935 |
| Direct costs | 10 | 33,604 | 20,596 | 73,914 | 128,114 | 91,426 |
| Depreciation | 17 | 3,350 | 3,350 | 636 | 7,336 | 7,754 |
| Support costs | 11 | 13,637 | 13,637 | 37,658 | 64,932 | 56,773 |
| | | <u>72,606</u> | <u>76,649</u> | <u>505,428</u> | <u>654,683</u> | <u>597,888</u> |
| Attributable to: | | | | | | |
| Unrestricted funds | | 72,606 | 76,649 | 505,428 | 654,683 | 597,888 |
| Restricted funds | | - | - | - | - | - |
| | | <u>72,606</u> | <u>76,649</u> | <u>505,428</u> | <u>654,683</u> | <u>597,888</u> |

EXPENDITURE ON RAISING FUNDS – 2021 COMPARATIVES

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2022

8. EXPENDITURE ON CHARITABLE ACTIVITIES

| | Note | Advocacy & Members Events £ | Awareness Raising £ | Commercial Trading Activity Patient Support £ | Total 2022 £ | Total 2021 £ |
|--------------------|------|--------------------------------------|---------------------------|--|--------------------|--------------------|
| Staff costs | 15 | 397,795 | 115,422 | 262,147 | 775,364 | 709,051 |
| Direct costs | 10 | 116,131 | 35,513 | - | 151,644 | 65,511 |
| Research grants | 12 | 219,368 | - | - | 219,368 | - |
| Depreciation | 17 | 16,753 | 5,027 | - | 21,780 | 21,278 |
| Support costs | 11 | 68,186 | 20,456 | - | 88,642 | 91,255 |
| | | <u>818,233</u> | <u>176,418</u> | <u>262,147</u> | <u>1,256,798</u> | <u>887,095</u> |
| Attributable to: | | | | | | |
| Unrestricted funds | | 515,669 | 176,418 | 262,147 | 954,234 | 462,092 |
| Restricted funds | | <u>302,564</u> | <u>-</u> | <u>-</u> | <u>302,564</u> | <u>425,003</u> |
| | | <u>818,233</u> | <u>176,418</u> | <u>262,147</u> | <u>1,256,798</u> | <u>887,095</u> |

EXPENDITURE ON CHARITABLE ACTIVITIES – 2021 COMPARATIVES

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2022

9. OTHER EXPENDITURE

| | Note | Management & Governance 2022 £ | Total 2022 £ | Management & Governance 2021 £ | Total 2021 £ |
|--------------------|------|---|--------------------|---|--------------------|
| Staff costs | 15 | 53,456 | 53,456 | 49,504 | 49,504 |
| Direct costs | 10 | 20,509 | 20,509 | 20,794 | 20,794 |
| Depreciation | 17 | 5,025 | 5,025 | 4,552 | 4,552 |
| Support costs | 11 | 20,456 | 20,456 | 21,418 | 21,418 |
| | | <u>99,446</u> | <u>99,446</u> | <u>96,268</u> | <u>96,268</u> |
| Attributable to: | | | | | |
| Unrestricted funds | | 94,800 | 94,800 | 96,268 | 96,268 |
| Restricted funds | | 4,646 | 4,646 | - | - |
| | | <u>99,446</u> | <u>99,446</u> | <u>96,268</u> | <u>96,268</u> |

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

10. ALLOCATION OF DIRECT COSTS

| | Note | Total Funds 2022 £ | Total Funds 2021 £ |
|---------------------------------------|------|-----------------------------|-----------------------------|
| Conference and expert meetings | | - | 1,876 |
| Support & support events | | 107,743 | 14,586 |
| Communications | | 40,136 | 40,047 |
| MPS awareness | | 1,945 | 8,459 |
| Fundraising expenses | | 20,596 | 14,464 |
| Donations and tributes in memory | | 1,640 | 224 |
| Management & Governance | | 20,509 | 20,794 |
| Survey costs | | 73,914 | 43,482 |
| Grant consultancy costs | | 33,604 | 33,480 |
| Patient welfare gifts | | 180 | 319 |
| | | <u>300,267</u> | <u>177,731</u> |
| Attributable to raising funds | 7 | 128,114 | 91,426 |
| Attributable to charitable activities | 8 | 151,644 | 65,511 |
| Attributable to other costs | 9 | 20,509 | 20,794 |
| | | <u>300,267</u> | <u>177,731</u> |

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2022

11. ALLOCATION OF SUPPORT COSTS

| | Note | 2022 £ | 2021 £ |
|---------------------------------------|------|----------------|----------------|
| Recruitment & training costs | | 8,118 | 18,139 |
| General office expenses | | 71,657 | 58,652 |
| Insurance | | 19,292 | 19,936 |
| Subscriptions | | 1,106 | 437 |
| Staff welfare | | 7,748 | 8,788 |
| Computer expenses and software | | 25,867 | 24,784 |
| Professional fees | | 8,658 | 12,350 |
| Bank charges | | 4,387 | 7,432 |
| Bad debts | | - | - |
| Travel and subsistence | | 8,644 | 2,411 |
| Consultancy expenses | | 9,853 | 9,317 |
| Auditors remuneration | | 8,700 | 7,200 |
| Loss on disposal of asset | | - | - |
| | | <u>174,030</u> | <u>169,446</u> |
| Attributable to raising funds | 7 | 64,932 | 56,773 |
| Attributable to charitable activities | 8 | 88,642 | 91,255 |
| Attributable to other costs | 9 | 20,456 | 21,418 |
| | | <u>174,030</u> | <u>169,446</u> |

12. GRANTS PAYABLE

| | 2022 £ | 2021 £ |
|---------------------------------------|----------------|-------------|
| Grants and donations | <u>219,368</u> | <u>-</u> |
| Grants payable to institutions | | |
| | 2022 | 2021 |
| | £ | £ |
| Research grants | <u>214,455</u> | <u>-</u> |

In 2022, grants were awarded for six projects which covered topics such as the link between physical activity and mental health in adults with Fabry disease, and the development of a mathematical model to calculate the risk of worsening airway and lung problems in people with MPS IVA Morquio. Grants payable costs have all been attributed to charitable activity expenditure.

13. NET INCOME/(EXPENDITURE)

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

| | 2022 £ | 2021 £ |
|---|---------------|---------------|
| Auditors' remuneration | 6,000 | 6,000 |
| Auditors' remuneration – non audit services | 1,200 | 1,200 |
| Depreciation | <u>34,141</u> | <u>33,584</u> |

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2022

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 2022 these totalled £1,043 (2021: £1,560) for all trustees.

15. STAFF COSTS

| | Group | | Charity | |
|-----------------------|------------------|------------------|----------------|----------------|
| | 2022 | 2021 | 2022 | 2021 |
| | £ | £ | £ | £ |
| Wages and salaries | 1,113,275 | 1,051,363 | 546,730 | 493,156 |
| Social security costs | 117,651 | 101,771 | 56,134 | 44,105 |
| Other pension costs | 52,195 | 47,356 | 24,890 | 22,713 |
| | <u>1,283,121</u> | <u>1,200,490</u> | <u>627,754</u> | <u>559,974</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 | |
|-------------------------------|-----------|-----------|-----------|-----------|
| | 2022 | 2021 | 2022 | 2021 |
| | £ | £ | £ | £ |
| Chief executives | 2 | 2 | 1 | 1 |
| Administration | 5 | 4 | 5 | 4 |
| Advice, information & support | 14 | 12 | 14 | 12 |
| Commercial trading operation | 13 | 15 | - | - |
| | <u>34</u> | <u>33</u> | <u>20</u> | <u>17</u> |

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

| | Group | | Charity | |
|---------------------------------|----------|----------|----------|----------|
| | 2022 | 2021 | 2022 | 2021 |
| | £ | £ | £ | £ |
| In the band £90,001 - £100,000 | 1 | 1 | 1 | 1 |
| In the band £120,001 - £130,000 | - | 1 | - | - |
| In the band £130,001 - £140,000 | 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 £359,893 (2021: £399,366). The highest paid employee of the charity had accrued £5,048 (2021: £4,760) in employer pension contributions and the highest paid employee of the group had accrued £6,555 (2021: £6,439) in employer pension contributions.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2022

16. 2021 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

| | Note | Unrestricted funds £ | Restricted funds £ | 2022 Total funds £ | 2021 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 grants & donations | 7 | 71,148 | - | 71,148 | 63,563 |
| Fundraising activities | | 69,045 | - | 69,045 | 74,782 |
| Trading activities | | 457,695 | - | 457,695 | 542,882 |
| | | 597,888 | - | 597,888 | 681,227 |
| <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 | | 256,206 | - | 256,206 | 167,301 |
| | | 462,092 | 425,003 | 887,095 | 779,958 |
| <i>Other costs</i> | | 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 |

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2022

17. TANGIBLE FIXED ASSETS

| Group | Freehold Land and buildings | Plant and Equipment | Totals |
|------------------------|--|--------------------------------|------------------|
| COST | £ | £ | £ |
| At 1 January 2022 | 1,435,389 | 63,476 | 1,498,865 |
| Additions | - | 6,662 | 6,662 |
| Disposals | - | - | - |
| At 31 December 2022 | <u>1,435,389</u> | <u>70,138</u> | <u>1,505,527</u> |
| DEPRECIATION | | | |
| At 1 January 2022 | 379,577 | 57,551 | 437,128 |
| Charge for year | 28,708 | 5,433 | 34,141 |
| Eliminated on disposal | - | - | - |
| At 31 December 2022 | <u>408,285</u> | <u>62,984</u> | <u>471,269</u> |
| NET BOOK VALUE | | | |
| At 31 December 2022 | <u>1,027,104</u> | <u>7,154</u> | <u>1,034,258</u> |
| At 31 December 2021 | <u>1,055,812</u> | <u>5,925</u> | <u>1,061,737</u> |
| Charity | Freehold Land and buildings | Plant and Equipment | Totals |
| COST | £ | £ | £ |
| At 1 January 2022 | 1,435,389 | 52,862 | 1,488,251 |
| Additions | - | 6,662 | 6,662 |
| Disposals | - | - | - |
| At 31 December 2022 | <u>1,435,389</u> | <u>59,524</u> | <u>1,494,913</u> |
| DEPRECIATION | | | |
| At 1 January 2022 | 379,577 | 48,209 | 427,786 |
| Charge for year | 28,708 | 4,797 | 33,505 |
| Eliminated on disposal | - | - | - |
| At 31 December 2022 | <u>408,285</u> | <u>53,006</u> | <u>461,291</u> |
| NET BOOK VALUE | | | |
| At 31 December 2022 | <u>1,027,104</u> | <u>6,518</u> | <u>1,033,622</u> |
| At 31 December 2021 | <u>1,055,812</u> | <u>4,653</u> | <u>1,060,465</u> |

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 2022

18. FIXED ASSET INVESTMENTS

| | 2022 Group £ | 2022 Charity £ | 2021 Group £ | 2021 Charity £ |
|---------------------------|--------------------|----------------------|--------------------|----------------------|
| Shares in subsidiary | - | 2 | - | 2 |
| Donated jewellery | 6,100 | 6,100 | 6,100 | 6,100 |
| Investments in bank bonds | 311,026 | 311,026 | 309,248 | 309,248 |
| | <u>317,126</u> | <u>317,128</u> | <u>315,348</u> | <u>315,350</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 | |
|--------------------------------------|------------------------|----------------|--|-----------|
| | 2022 £ | 2021 £ | 2022 £ | 2021 £ |
| Fixed assets | 636 | 1,272 | - | - |
| Current assets | 847,669 | 942,831 | 1 | 1 |
| Current liabilities | (848,304) | (944,102) | - | - |
| Aggregate share capital and reserves | <u>1</u> | <u>1</u> | <u>1</u> | <u>1</u> |
| Net income from trading activities | <u>232,465</u> | <u>133,218</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 £311,027 in fixed business bonds, which are due to mature within less than one year. Of the £311,027 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 2022

19. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

| | 2022 | 2022 | 2021 | 2021 |
|------------------------------------|----------------|----------------|----------------|----------------|
| | Group | Charity | Group | Charity |
| | £ | £ | £ | £ |
| Trade debtors | 327,585 | 5,029 | 260,428 | 120 |
| Amounts owed by group undertakings | - | 432,465 | - | 333,217 |
| Other debtors | 2,249 | 1,988 | 10,257 | 6,930 |
| Prepayments and accrued income | 38,718 | 8,119 | 44,412 | 14,412 |
| | <u>368,552</u> | <u>447,601</u> | <u>315,097</u> | <u>354,679</u> |

20. CASH AT BANK AND IN HAND

| | 2022 | 2022 | 2021 | 2021 |
|-----------------------------|------------------|----------------|------------------|------------------|
| | Group | Charity | Group | Charity |
| | £ | £ | £ | £ |
| Cash held in parent charity | 793,648 | 793,648 | 1,160,156 | 1,160,157 |
| Cash held in subsidiary | 494,252 | - | 541,271 | - |
| | <u>1,287,900</u> | <u>793,648</u> | <u>1,701,427</u> | <u>1,160,157</u> |

21. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

| | 2022 | 2022 | 2021 | 2021 |
|------------------|----------------|----------------|----------------|----------------|
| | Group | Charity | Group | Charity |
| | £ | £ | £ | £ |
| Trade creditors | 32,398 | 12,034 | 19,087 | 6,013 |
| Other creditors | 428,997 | 35,724 | 546,205 | 58,321 |
| Accrued expenses | 17,113 | 14,913 | 9,305 | 7,305 |
| | <u>478,508</u> | <u>62,667</u> | <u>574,597</u> | <u>71,639</u> |

Included within other creditors is deferred income of £187,140 (2021: £197,730). 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 2022 has been subsequently recognised as income in 2021.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

| | 2022 | 2022 | 2022 | 2021 | 2021 | 2021 |
|---------------------|---------------------|-------------------|------------------|---------------------|-------------------|------------------|
| | Unrestricted | Restricted | Total | Unrestricted | Restricted | Total |
| | funds | funds | Funds | funds | Funds | Funds |
| | £ | £ | £ | £ | £ | £ |
| Fixed assets | 1,034,258 | - | 1,034,258 | 1,061,737 | - | 1,061,737 |
| Investments | 317,126 | - | 317,126 | 315,348 | - | 315,348 |
| Current assets | 1,418,839 | 237,613 | 1,656,452 | 1,841,122 | 175,402 | 2,016,524 |
| Current liabilities | (478,508) | - | (478,508) | (574,597) | - | (574,597) |
| | <u>2,291,715</u> | <u>237,613</u> | <u>2,529,328</u> | <u>2,643,610</u> | <u>175,402</u> | <u>2,819,012</u> |

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2022

23. STATEMENT OF FUNDS

Group

| | Funds at 1 January 2022 | Income | Expenditure | Fund Transfers | Funds at 31 December 2022 |
|----------------------------------|-------------------------------|-------------------------|---------------------------|-------------------|---------------------------------|
| <i>Unrestricted funds</i> | | | | | |
| General charitable fund | 750,000 | 1,351,823 | (1,351,823) | - | 750,000 |
| Property fund | 1,055,811 | - | (28,708) | - | 1,027,103 |
| Designated funds | | | | | |
| Research fund | 367,297 | - | (219,368) | - | 147,929 |
| Service development fund | 270,502 | - | (103,818) | - | 166,684 |
| Building refurbishment fund | 100,000 | - | - | - | 100,000 |
| Christine Lavery memorial fund | 100,000 | - | - | - | 100,000 |
| | <u>837,799</u> | <u>-</u> | <u>(323,186)</u> | <u>-</u> | <u>514,613</u> |
| Total unrestricted funds | <u>2,643,610</u> | <u>1,351,823</u> | <u>(1,703,717)</u> | <u>-</u> | <u>2,291,716</u> |
| <i>Restricted funds</i> | | | | | |
| MPS restricted fund | 50,109 | 369,420 | (302,564) | - | 116,965 |
| LSD restricted fund | 15,916 | - | (4,646) | - | 11,270 |
| Research restricted fund | 109,377 | - | - | - | 109,377 |
| Total restricted funds | <u>175,402</u> | <u>369,420</u> | <u>(307,210)</u> | <u>-</u> | <u>237,612</u> |
| Total Funds | <u>2,819,012</u> | <u>1,721,243</u> | <u>(2,010,927)</u> | <u>-</u> | <u>2,529,328</u> |

Charity

| | Funds at 1 January 2022 | Income | Expenditure | Fund Transfers | Funds at 31 December 2022 |
|----------------------------------|-------------------------------|-----------------------|-------------------------|-------------------|---------------------------------|
| <i>Unrestricted funds</i> | | | | | |
| General charitable fund | 750,000 | 325,658 | (325,658) | - | 750,000 |
| Property fund | 1,055,811 | - | (28,708) | - | 1,027,103 |
| Designated funds | | | | | |
| Research fund | 367,297 | - | (219,368) | - | 147,929 |
| Service development fund | 270,502 | - | (103,818) | - | 166,684 |
| Building refurbishment fund | 100,000 | - | - | - | 100,000 |
| Christine Lavery memorial fund | 100,000 | - | - | - | 100,000 |
| | <u>837,799</u> | <u>-</u> | <u>(323,186)</u> | <u>-</u> | <u>514,613</u> |
| Total unrestricted funds | <u>2,643,610</u> | <u>325,658</u> | <u>(677,552)</u> | <u>-</u> | <u>2,291,716</u> |
| <i>Restricted funds</i> | | | | | |
| MPS restricted fund | 50,109 | 369,420 | (302,564) | - | 116,965 |
| LSD restricted fund | 15,916 | - | (4,646) | - | 11,270 |
| Research restricted fund | 109,377 | - | - | - | 109,377 |
| Total restricted funds | <u>175,402</u> | <u>369,420</u> | <u>(307,210)</u> | <u>-</u> | <u>237,612</u> |
| Total Funds | <u>2,819,012</u> | <u>695,078</u> | <u>(984,762)</u> | <u>-</u> | <u>2,529,328</u> |

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2022

23. STATEMENT OF FUNDS (CONTINUED) 2021 COMPARITIVES

Group

| | Funds at 1 January 2021 | Income | Expenditure | Fund Transfers | Funds at 31 December 2021 |
|---------------------------|-------------------------------|------------------|--------------------|-------------------|---------------------------------|
| Unrestricted funds | | | | | |
| General charitable | 750,000 | 1,160,891 | (1,127,539) | (33,352) | 752,815 |
| Property fund | 1,084,520 | - | (28,709) | - | 1,055,811 |
| Research fund | 367,297 | - | - | - | 367,297 |
| Service development | 237,150 | - | - | 33,352 | 270,502 |
| Building refurbishment | 100,000 | - | - | - | 100,000 |
| Christine Lavery | 100,000 | - | - | - | 100,000 |
| | <u>804,447</u> | <u>-</u> | <u>-</u> | <u>33,352</u> | <u>837,799</u> |
| Total unrestricted | <u>2,638,967</u> | <u>1,160,891</u> | <u>(1,156,248)</u> | <u>-</u> | <u>2,366,043</u> |
| Restricted funds | | | | | |
| MPS restricted | 192,757 | 282,355 | (425,003) | - | 31,921 |
| LSD restricted | 15,916 | - | - | - | 16,749 |
| Research restricted | 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 | 750,000 | 446,990 | (413,638) | (33,352) | 750,000 |
| Property fund | 1,084,520 | - | (28,709) | - | 1,055,811 |
| Research fund | 367,297 | - | - | - | 367,297 |
| Service development | 237,150 | - | - | 33,352 | 270,502 |
| Building refurbishment | 100,000 | - | - | - | 100,000 |
| Christine Lavery | 100,000 | - | - | - | 100,000 |
| | <u>804,446</u> | <u>-</u> | <u>-</u> | <u>-</u> | <u>837,769</u> |
| Total unrestricted | <u>2,638,967</u> | <u>446,990</u> | <u>(442,347)</u> | <u>-</u> | <u>2,643,610</u> |
| Restricted funds | | | | | |
| MPS restricted | 192,757 | 282,355 | (425,003) | - | 50,109 |
| LSD restricted | 15,916 | - | - | - | 15,916 |
| Research restricted | 109,377 | - | - | - | 109,377 |
| Total restricted | <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>729,345</u> | <u>(867,350)</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 2022

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 £432,465 (2021: £333,217). All the profits of MPS Commercial Limited for the period have been distributed by Gift Aid to the charity, these totalled £232,465 (2021: £133,218).

Rent and recharges of £20,000 (2022: £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 (2021: £200,000) on which interest of £6,125 (2021: £4,200) was charged.

During the year donations and pledges of £ 1,540 (2021: £1,503) were received from trustees of the charity.

25. ULTIMATE CONTROLLING PARTY

The board of trustees controls the charity.