

Charity registration number 1143472 (England and Wales)

Charity registration number SCO41012 (Scotland)

Company registration number 07726882 (England and Wales)

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES
ANNUAL REPORT AND CONSOLIDATED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023



SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Katy Brown Sarah Burgess Judith Evans James Garthwaite Prof Simon Heales Prof Derralynn Hughes David Patton Phillip Pearson Wilma Robins Fiona Stewart Prof Bryan Winchester	
Secretary	Toni Ellerton	
Senior management	Robert Stevens John Illankovan Sophie Thomas Anna Featherstone Steve Cotterell Toni Ellerton Barbara Cotterell Helen Crawley Tom Kenny	Group Chief Executive Head of Group Finance Senior Head of Patient Services and Clinical Liaisons Head of Fundraising Head of Support and Advocacy Executive Assistant and Company Secretary HR Lead Head of Communications RDRP CEO - Left 18 July 2023
Charity number (England and Wales)	1143472	
Charity number (Scotland)	SCO41012	
Company number	07726882	
Registered office	MPS House Repton Place White Lion Road Amersham Buckinghamshire HP7 9LP	
Auditor	Xeinadin Audit Limited 2 Hilliards Court Chester Business Park Chester Cheshire CH4 9QP	

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

LEGAL AND ADMINISTRATIVE INFORMATION

Bankers

Barclays Bank Plc
United Kingdom House
7th Floor
180 oxford Street
London
W1B 1EA

Solicitors

Womble Bond Dickinson
4 More
London Riverside
London
SE1 2AU

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONTENTS

	Page
Chairman's Statement	1
Trustees' report	2 - 10
Statement of trustees' responsibilities	11
Independent auditor's report	12 - 14
Statement of financial activities - Group	15 - 16
Balance sheet - Group	17
Balance sheet - Charity	18
Statement of cash flows - Group	19
Notes to the financial statements	20 - 38

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CHAIRMAN'S STATEMENT

FOR THE YEAR ENDED 31 DECEMBER 2023

After all the excitement of our 40th Anniversary Year in 2022 we have used 2023 as a year to regroup and plan for the future. In doing so we released our strategic plan for the next three years which set the focus of our support on mental health and wellbeing. We continue to put our members at the centre of everything we do but with a more proactive approach – rather than purely needs-led we hope to anticipate those needs and be ready with support. The strategy also continues our focus on early diagnosis, through newborn screening and other diagnostic tools that become available, and aims to embed standards across the specialist centres that our members turn to.

This year also brought the culmination of many years of work with NICE (The National Institute for Health and Care Excellence) and NHS England on highly-specialised treatments, including a treatment for infantile lysosomal acid lipase deficiency (LAL D Wolman disease), an enzyme replacement therapy for Fabry disease and life-changing medication for the treatment of alpha mannosidosis.

We supported our community through six face-to-face events, which included new additions of a parent wellbeing retreat and a social weekend for adults with an MPS or related condition. It's evident from feedback that our community appreciate the opportunity to meet one another in a relaxed environment and we know how important it is to offer these in-person meetings. We also appreciate that not everyone can attend an in-person event and so introducing the Support Hub was another way to bring our community together. The Hub lives on Facebook and is a forum for people with these rare conditions to provide peer support in a safe place and where our support team can be present with a listening ear.

This year of regrouping also gave us the opportunity to take a fresh look at our website. The new site launched at the end of 2023 and offers a cleaner and more consistent look with improved navigation. The changes were based on feedback from our community and key stakeholders allowing us to offer a tailored site that works for the people using it.

We hope to continue to build on these foundations in 2024 and look forward to another year of improving for our community.



Judith Evans

Chair of Trustees

Date: 22/06/24...

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 DECEMBER 2023

The trustees (who are also the directors of the charity for the purposes of the Companies Act) present their annual report together with the audited financial statements of the Society for Mucopolysaccharide Diseases (the charity and the group) for the year ended 31 December 2023.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of Association], the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) 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 regulations

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

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

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, Geleco 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 DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

Achievements and performance

Access to Exceptional Support and Advice

Support and Advocacy Team

We continue to put the people we support at the centre of everything we do and have committed to focus on rare lives. In 2023 we welcomed 61 new members to the MPS Society who join for free and are given specialised practical and emotional support for their whole family. We now support over 1800 families from diagnosis, through living with the condition, dealing with key life transitions and milestones, to bereavement and beyond.

We completed more than 350 pieces of in-depth work last year across health and social care, education, benefits as well as emotional support and including health and well-being. As well as members we supported clinics at GOSH, Manchester and Birmingham children's hospitals.

Support Hub

We realised a need for a forum type online community and introduced the Support Hub on Facebook in response. We now have 205 members who have joined the Society in this way. The Hub allows peer support for the community but with Support and Advocacy Officers available to mediate, add to discussions and prompt questions.

Events

Throughout 2023 we held many face-to-face support events for our families and received lovely feedback following each one. Our families were unanimous in expressing the positive impact meeting other families and being able to share stories, tips, and support has on them.

Our aim is to provide our members and families with appropriate and accessible events which offer them fun but also an opportunity to meet up and share experiences. It's also an excellent opportunity for our Support and Advocacy Team to meet with members in a casual setting.

This year we held six events in total including new additions of a wellbeing retreat for parents and the social get together for adult patients alongside our usual weekend of remembrance, trip to an amusement park and Christmas events.

"As ever a huge part of the benefit came from meeting with other parents and having long in-depth conversations that just aren't possible online."

Parent feedback from the Wellbeing retreat

"It was lovely to see old faces, meet those I'd only spoken to online, and meet others I'd never met before! Good food, great company, will definitely love to attend more events like this."

Member feedback from social weekend for adults

"I'm glad I built up the courage to attend. I was immensely proud of returning to the childhood wood which brought back so many good memories despite the sadness. It was a really special time for me where I was able to catch up with very special friends and to also pay thanks to all of you for doing so well with the charity and the families."

Member feedback from Weekend of Remembrance and Hope

As well as this we worked on the Fabry Matters Conference which happened in 2024, supported the Gaucher conference and represented our community at the Fabry International Network (FIN) Conference.

Mental health support

In 2023 we worked with Rare Minds to provide 186 counselling sessions for 26 people living with MPS, Fabry or a related condition having identified this as an area of support our community is missing.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

Access to world-class clinical care

Clinical Scientific Advisory Committee

CSAC or Clinical Scientific Advisory Committee is our dedicated group of trustees and staff who consider research applications from medical and healthcare professionals to benefit our community.

In 2023, Dr Simon Jones joined as a member of CSAC bringing great depth and breadth of knowledge and experience.

Professor Uma Ramaswami's work which we helped fund, was accepted as a poster at WORLD 2024 and we were very proud to hear that one of our awardees won a prize at the British Inherited Metabolic Disease Group meeting for best presentation of papers presented.

This year also saw the first award of a summer studentship funded by the Christine Lavery Memorial Fund to mark 40 years of the MPS Society, to commemorate Christine's dedication to research, and to hopefully inspire interest from the up-and-coming generation.

On October 10th, we held our first virtual CSAC open day. CSAC Chair, Dr Fiona Stewart, used this online meeting to explain the function of CSAC and gave space for some funded projects to share their findings.

Since CSAC was established, we have awarded £355,956.75 in grants across 10 projects.

Access to effective treatments

Highly-specialised treatments

As part of her role, our Senior Head of Patient Services and Clinical Liaisons works alongside other patient organisations and pharmaceutical companies to make sure highly-specialised treatments that are trialled successfully make it through the rigorous process NICE (The National Institute for Health and Care Excellence) and NHS England need to recommend these treatments for use with our conditions.

In the past year we have successfully campaigned for the following treatments.

Vestronidase alfa (Mepsevii®) for MPS VII was approved for routine commissioning for infants in November 2022. This is the first ERT approved outside of NICE (due to small patient numbers in the UK this was a separate process through NHS England) and is intended to be a bridging therapy for neonates and infants before Haematopoietic stem cell transplantation (HSCT).

Velmanase alfa (Lamzede®) to treat people with alpha mannosidosis who commence treatment under the age of 18 years. NICE approved the treatment in November 2023 after a five-year review process.

Sebelipase alfa (Kanuma®) was recommended as an option for long-term enzyme replacement therapy for people with infantile lysosomal acid lipase deficiency (LAL D) if they are two years or younger when treatment starts in November 2023 after nearly eight years in review with NICE.

Pegunigalsidase alfa (Elfabrio®) for Fabry adults age 18 years and over was recommended as a treatment option in September 2023. In November 2023 the Scottish Medicines Consortium (SMC) released their decision not to recommend pegunigalsidase alfa (Elfabrio®) for the long-term treatment of adult patients with a confirmed diagnosis of Fabry. We remain committed to working with all parties to ensure that our members in Scotland have equitable access to therapies.

Newborn screening

We continue to work with the Newborn Screen Collaborative on three main priorities: 1) a review of the UK NBS policy and processes, 2) conducting an evidence and progress review, 3) political engagement by aligning work of individual collaborative members. In 2023 we supported the launch of the comedy short film, A Rare Find, which aimed to raise awareness and create a conversation in around the subject of newborn screening.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

Operating effective processes

In order to carry out work toward our goals in 2023 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.

Fundraising and donations

Individual donations - We are very grateful to our supporters who continue to donate to us regularly. In 2023, we received over £23,000 from regular donations and payroll giving schemes. We also received over £9,000 from donations and tributes in memory of loved ones, over £3,000 in one off donations and £133,228 from legacy donations.

Community fundraising - We love hearing about all the creative ways our supporters raise funds for us. In 2023, we raised over £27,000 from supporters' own events plus a further £16,393 from community groups and £3,735 from Facebook birthday fundraisers.

Events and challenges – We are pleased to have raised over £70,000 from challenge events in 2023, 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 and our donors we raised over £28,000 towards funding our 2024 advocacy support events, to include counselling, wellness sessions and peer support groups, as well as social events for children and young people living with a rare genetic condition.

MPS Awareness Week - During our 2023 MPS Awareness Week, we raised £11,940 from schools, community groups, companies and individuals. We collaborated with the International MPS Network to share stories on the theme of as we know the journey to an MPS diagnosis can be long and complex. The sooner the signs of an MPS condition are identified, the sooner the patient can receive a diagnosis and any available treatment can commence.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

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 2023 include The W E Dunn Trust, Pilkington Charities Fund, Annie Tranmer Charitable Trust, Hospital Saturday Fund, Christopher & Elspeth Thomas Charitable Trust, JTH Charitable Trust, Oakdale Trust, James Knott Trust, Sylvia Aitken Charitable Trust, Clover Trust, Joseph Strong Frazer Trust, Enkalon Foundation, W O Street Charitable Foundation, Zochonis Charitable Trust, Roland Callingham Foundation, Geoff and Fiona Squire Foundation, Constance Travis Charitable Trust, Sandra Charitable Trust, Strangward Trust, Baddiley Consolidated Charities, Eveson Trust, Florence Turner Charitable Trust, John Avins Trust, Bruce Wake Trust, Bowen Lodge Freemasons.

We were very grateful to receive financial contributions during 2023 from the following pharmaceutical companies towards various aspects of our patient support services and projects:

Amicus Therapeutics UK Limited, BioMarin, Denali, JCR Pharmaceuticals, Sanofi, Orchard Therapeutics, REGENXBIO, Takeda UK, Ultragenyx Pharmaceuticals have provided funding to MPS Society in support of 2023 patient projects but have had no input into contents or output. Chiesi has provided an arm's length grant to MPS Society in support of 2023 patient projects but have had no input into contents or output.

Takeda UK Ltd provided funding in 2023 to develop and print a decision support aid. Whilst the MPS Society have had full editorial control, Takeda have helped develop content, reviewed the content for technical accuracy and compliance with the ABPI Code of Practice.

Our grants and donations from charitable trusts and foundations came to £199,096; Grants and donation from pharmaceutical companies came to £177,800; and grants and donations from other sources came to £42,550 giving a total of £419,446 from these sources.

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 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.

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 DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

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 £602,741 in comparison to £471,717 in 2022. Receipts from donations £68,062 compared with £174,931 in 2022. This year legacies of £133,228 were received whereas £15,208 of legacies were received in 2022.

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 2023, MPS Commercial were able to donate £40,387 (2022: £232,465) 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 2023 was £1,812,981(2022: £1,721,243) compared with total expenditure of £1,996,359 (2022: £2,010,927) resulting in a deficit of £183,378 (2022: £289,684).

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

Reserves policy

In the year, ending 31 December 2023 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 doing so, 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 £730,696 (2022: £667,547). The level of free reserves as at 31 December 2023 amounted to £742,346 (2022: £742,845) which amounts to 6 months of overall expenditure of the society.

Major risks

The trustees have assessed the major risks to which the charity is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

Plans for future periods

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.

Structure, governance and management

The Society is controlled by its governing document, the Memorandum and Articles of Association, 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.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Katy Brown
Sarah Burgess
Judith Evans
James Garthwaite
Prof Simon Heales
Prof Derralynn Hughes
David Patton
Phillip Pearson
Wilma Robins
Fiona Stewart

Recruitment and appointment of new trustees

New trustees are elected by the directors/trustees and typically hold office for six years.

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 DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

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.

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.

Auditor

In accordance with the company's articles, a resolution proposing that Xeinadin Audit Limited be reappointed as auditor of the company will be put at a General Meeting.

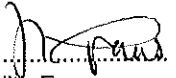
SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)
FOR THE YEAR ENDED 31 DECEMBER 2023

Disclosure of information to auditor

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 trustees' report was approved by the Board of Trustees.


.....
Judith Evans
Trustee

Date: 22/06/24

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

STATEMENT OF TRUSTEES' RESPONSIBILITIES

FOR THE YEAR ENDED 31 DECEMBER 2023

The trustees, who are also the directors of Society for Mucopolysaccharide Diseases for the purpose 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 charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS AND TRUSTEES OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Opinion

We have audited the financial statements of Society for Mucopolysaccharide Diseases (the charitable company) and its subsidiaries (the group) for the year ended 31 December 2023 which comprise the group statement of financial activities, the group balance sheet, the charitable company balance sheet, the group statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and charitable company's affairs as at 31 December 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; 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 (as amended).

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

Conclusions relating to going concern

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 other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. 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 course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS AND TRUSTEES OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Opinions on other matters prescribed by the Companies Act 2006

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

- the information given in the trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the trustees' report 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 charity and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate and proper 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 charity 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 charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue 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.

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS AND TRUSTEES OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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.


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 is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

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 and to the regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and trustees those matters we are required to state to them in an auditor's 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, the charitable company's members as a body, and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Helen Furlong FCGA (Senior Statutory Auditor)
for and on behalf of Xeinadin Audit Limited

8.7.24

Accountants
Statutory Auditor

2 Hilliards Court
Chester Business Park
Chester
Cheshire
CH4 9QP

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 DECEMBER 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Income from:							
Donations and legacies	4	201,290	-	201,290	190,139	-	190,139
Activities for generating funds							
Advocacy support	5	278,845	247,396	526,241	99,797	277,170	376,967
Physiological support	5	-	15,000	15,000	-	33,500	33,500
MPS Awareness	5	-	20,000	20,000	-	25,000	25,000
Family support special events	5	-	41,500	41,500	-	33,750	33,750
Other income	5	-	-	-	2,500	-	2,500
Other trading activities	6	958,230	-	958,230	1,025,521	-	1,025,521
Investments	7	50,720	-	50,720	33,866	-	33,866
Total income		1,489,085	323,896	1,812,981	1,351,823	369,420	1,721,243
Expenditure on:							
Raising funds							
Fundraising and publicity	8	158,534	-	158,534	149,255	-	149,255
Commercial trading activity	8	612,973	-	612,973	505,428	-	505,428
		771,507	-	771,507	654,683	-	654,683
Charitable activities							
Advocacy services & member events	9	355,289	359,363	714,652	368,152	307,210	675,362
Awareness raising	9	184,522	-	184,522	199,367	-	199,367
Trading activities –							
Patients support	9	274,923	-	274,923	262,147	-	262,147
Research grants	9	50,755	-	50,755	219,368	-	219,368
Total charitable expenditure		865,489	359,363	1,224,852	1,049,034	307,210	1,356,244
Total expenditure		1,636,996	359,363	1,996,359	1,703,717	307,210	2,010,927

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 DECEMBER 2023

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Notes						
Net expenditure and movement in funds	(147,911)	(35,467)	(183,378)	(351,894)	62,210	(289,684)
Reconciliation of funds:						
Fund balances at 1 January 2023	2,291,716	237,612	2,529,328	2,643,610	175,402	2,819,012
Fund balances at 31 December 2023	<u>2,143,805</u>	<u>202,145</u>	<u>2,345,950</u>	<u>2,291,716</u>	<u>237,612</u>	<u>2,529,328</u>

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

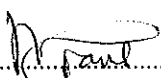
SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED BALANCE SHEET

AS AT 31 DECEMBER 2023

	Notes	2023		2022	
		£	£	£	£
Fixed assets					
Tangible assets	15		1,006,049		1,034,258
Investments	16		628,497		317,126
			<u>1,634,546</u>		<u>1,351,384</u>
Current assets					
Debtors	18	540,268		368,552	
Cash at bank and in hand		731,411		1,287,900	
		<u>1,271,679</u>		<u>1,656,452</u>	
Creditors: amounts falling due within one year	19	560,275		478,508	
Net current assets			<u>711,404</u>		<u>1,177,944</u>
Total assets less current liabilities			<u>2,345,950</u>		<u>2,529,328</u>
The funds of the charity					
Restricted income funds	21	202,145		237,612	
Unrestricted funds		2,143,805		2,291,716	
		<u>2,345,950</u>		<u>2,529,328</u>	

The financial statements were approved by the trustees on ... 22/06/24


.....
Judith Evans
Trustee

Company registration number 07726882 (England and Wales)

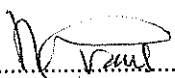
SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CHARITABLE COMPANY BALANCE SHEET

AS AT 31 DECEMBER 2023

	Notes	2023		2022	
		£	£	£	£
Fixed assets					
Tangible assets	15		1,002,408		1,033,622
Investments	16		628,499		317,128
			<u>1,630,907</u>		<u>1,350,750</u>
Current assets					
Debtors	18	256,749		447,601	
Cash at bank and in hand		553,229		793,648	
		<u>809,978</u>		<u>1,241,249</u>	
Creditors: amounts falling due within one year	19	94,935		62,671	
Net current assets			<u>715,043</u>		<u>1,178,578</u>
Total assets less current liabilities			<u>2,345,950</u>		<u>2,529,328</u>
The funds of the charity					
Restricted income funds	21		202,145		237,612
Unrestricted funds			2,143,805		2,291,716
			<u>2,345,950</u>		<u>2,529,328</u>

The financial statements were approved by the trustees on 02/01/24....



Judith Evans
Trustee

Company registration number 07726882 (England and Wales)

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 DECEMBER 2023

	Notes	2023 £	£	2022 £	£
Cash flows from operating activities					
Cash absorbed by operations	25		(289,575)		(438,953)
Investing activities					
Purchase of tangible fixed assets		(6,263)		(6,662)	
Proceeds from disposal of investments		(311,371)		(1,778)	
Investment income received		50,720		33,866	
		<hr/>		<hr/>	
Net cash (used in)/generated from investing activities			(266,914)		25,426
Net cash used in financing activities			<hr/>	<hr/>	-
			(556,489)		(413,527)
Net decrease in cash and cash equivalents					
Cash and cash equivalents at beginning of year			1,287,900		1,701,427
			<hr/>		<hr/>
Cash and cash equivalents at end of year			731,411		1,287,900
			<hr/> <hr/>		<hr/> <hr/>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2023

1 Accounting policies

Charity information

Society for Mucopolysaccharide Diseases is a 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.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's Memorandum and Articles of Association, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "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). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation 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 Going concern

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.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

1 Accounting policies (Continued)

1.3 Charitable funds

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.

1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

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 gift, 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.

Allocation of support costs

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

1 Accounting policies

(Continued)

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.

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).

1.6 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 the statement of financial activities.

1.7 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.

1.8 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.9 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

1 Accounting policies

(Continued)

1.10 Financial instruments

The charity 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 charity's balance sheet when the charity 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 charity's contractual obligations expire or are discharged or cancelled.

1.11 Taxation

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

1.12 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.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

2 Critical accounting estimates and judgements

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

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

3 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.

4 Income from donations and legacies

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Donations and gifts	68,062	174,931
Legacies receivable	133,228	15,208
	<u>201,290</u>	<u>190,139</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

5 Income from charitable activities

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Advocacy support						
Grants receivable	278,845	169,800	448,645	99,797	212,170	311,967
National Lottery community fund	-	77,596	77,596	-	65,000	65,000
Physiological support						
Grants receivable	-	15,000	15,000	-	33,500	33,500
MPS Awareness						
Grants receivable	-	20,000	20,000	-	25,000	25,000
Family support special events						
Grants receivable	-	41,500	41,500	-	33,750	33,750
Other income						
Grants receivable	-	-	-	2,500	-	2,500
	<u>278,845</u>	<u>323,896</u>	<u>602,741</u>	<u>102,297</u>	<u>369,420</u>	<u>471,717</u>

6 Income from other trading activities

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Survey income in subsidiary	479,497	456,623
Management fees in subsidiary	478,733	568,898
Other trading activities	<u>958,230</u>	<u>1,025,521</u>

7 Income from investments

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Rental income	29,917	29,951
Interest receivable	20,803	3,915
	<u>50,720</u>	<u>33,866</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

8 Expenditure on raising funds

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Fundraising and publicity		
Grant consultancy costs	6,026	33,604
Fundraising expenses	15,475	20,596
Staff costs	105,747	61,081
Depreciation and impairment	6,404	6,700
Support costs	24,882	27,274
	<u>158,534</u>	<u>149,255</u>
Trading costs		
Survey costs	41,936	73,914
Staff costs	412,384	393,220
Depreciation and impairment	2,456	636
Support costs	156,197	37,658
	<u>612,973</u>	<u>505,428</u>
Total costs	<u><u>771,507</u></u>	<u><u>654,683</u></u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

9 Expenditure on charitable activities

	Advocacy services & member events	Awareness raising	Trading activities – Patients support	Research grants	Total
	2023	2023	2023	2023	2023
	£	£	£	£	£
Direct costs					
Staff costs	412,202	118,862	274,923	-	805,987
Depreciation and impairment	16,009	4,802	-	-	20,811
Conference and expert meetings	133,157	-	-	-	133,157
Communication	2,150	15,369	-	-	17,519
MPS awareness	-	311	-	-	311
Donations and tributes in memory	429	-	-	-	429
Patient welfare gifts	111	-	-	-	111
	<u>564,058</u>	<u>139,344</u>	<u>274,923</u>	<u>-</u>	<u>978,325</u>
Research grants (see note 10)	-	-	-	50,755	50,755
Share of support and governance costs (see note 11)					
Support	57,075	17,122	-	-	74,197
Governance	93,519	28,056	-	-	121,575
	<u>714,652</u>	<u>184,522</u>	<u>274,923</u>	<u>50,755</u>	<u>1,224,852</u>
Analysis by fund					
Unrestricted funds	355,289	184,522	274,923	50,755	865,489
Restricted funds	359,363	-	-	-	359,363
	<u>714,652</u>	<u>184,522</u>	<u>274,923</u>	<u>50,755</u>	<u>1,224,852</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

9 Expenditure on charitable activities

(Continued)

Previous year:	Advocacy services & member events	Awareness raising	Trading activities – Patients support	Research grants	Total
	2022	2022	2022	2022	2022
	£	£	£	£	£
Direct costs					
Staff costs	397,795	115,422	262,147	-	775,364
Depreciation and impairment	16,753	5,027	-	-	21,780
Conference and expert meetings	107,743	-	-	-	107,743
Communication	6,568	33,568	-	-	40,136
MPS awareness	-	1,945	-	-	1,945
Donations and tributes in memory	1,640	-	-	-	1,640
Patient welfare gifts	180	-	-	-	180
	<u>530,679</u>	<u>155,962</u>	<u>262,147</u>	<u>-</u>	<u>948,788</u>
Grant funding of activities (see note 10)	-	-	-	219,368	219,368
Share of support and governance costs (see note 11)					
Support	54,834	16,450	-	-	71,284
Governance	89,849	26,955	-	-	116,804
	<u>675,362</u>	<u>199,367</u>	<u>262,147</u>	<u>219,368</u>	<u>1,356,244</u>
Analysis by fund					
Unrestricted funds	368,152	199,367	262,147	219,368	1,049,034
Restricted funds	307,210	-	-	-	307,210
	<u>675,362</u>	<u>199,367</u>	<u>262,147</u>	<u>219,368</u>	<u>1,356,244</u>

10 Grants payable

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.

-

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

11 Support costs allocated to activities

	2023 £	2022 £
Recruitment & Training costs	8,559	8,118
General office expenses	62,072	51,201
Insurance	13,895	19,292
Subscriptions	2,472	1,106
Staff welfare	14,875	7,748
Computer Expenses	32,764	25,867
Bank charges	5,149	4,387
Bad debts	100,000	-
Travel and subsistence	11,988	8,644
Consultancy expenses	20,163	9,853
Governance costs	104,914	116,804
	<u>376,851</u>	<u>253,020</u>
Analysed between:		
Fundraising	24,882	27,274
Trading	156,197	37,658
Advocacy services & member events	150,594	144,683
Awareness raising	45,178	43,405
	<u>376,851</u>	<u>253,020</u>
	<u>376,851</u>	<u>253,020</u>
	2023	2022
Governance costs comprise:	£	£
Staff costs	54,873	53,456
Depreciation	4,803	5,025
Audit fees	8,353	8,700
Legal and professional	6,193	8,658
Management costs	30,692	40,965
	<u>104,914</u>	<u>116,804</u>

12 Trustees

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 2023 these totalled £2,321 (2022: £1,043) for all trustees.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

13 Employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
Chief executives	2	2
Administration	5	5
Advice, information & support	16	14
Commercial trading operation	14	13
Total	37	34

Employment costs

	2023 £	2022 £
Wages and salaries	1,215,268	1,113,275
Social security costs	104,567	117,651
Other pension costs	59,156	52,195
	1,378,991	1,283,121

The number of employees whose annual remuneration was more than £60,000 is as follows:

	2023 Number	2022 Number
£90,001 - £100,000	1	1
£100,001 - £110,000	1	-
£130,001 - £140,000	-	1

Remuneration of key management personnel

The remuneration of key management personnel is as follows.

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 £334,300 (2022: £359,893). The highest paid employee of the charity had accrued £5,769 (2022: £5,048) in employer pension contributions and the highest paid employee of the group had accrued £5,477 (2022: £6,555) in employer pension contributions.

14 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

15 Tangible Fixed Assets - Group

	Freehold land and buildings £	Computers and equipment £	Total £
Cost			
At 1 January 2023	1,435,389	70,138	1,505,527
Additions	-	6,263	6,263
At 31 December 2023	1,435,389	76,401	1,511,790
Depreciation and impairment			
At 1 January 2023	408,285	62,981	471,266
Depreciation charged in the year	28,708	5,767	34,475
At 31 December 2023	436,993	68,748	505,741
Carrying amount			
At 31 December 2023	998,396	7,653	1,006,049
At 31 December 2022	1,027,104	7,154	1,034,258

Tangible Fixed Assets - Charity

	Freehold land and buildings £	Computers and equipment £	Total £
Cost			
At 1 January 2023	1,435,389	59,526	1,494,915
Additions	-	802	802
At 31 December 2023	1,435,389	60,328	1,495,717
Depreciation and impairment			
At 1 January 2023	408,285	72,957	481,242
Depreciation charged in the year	28,708	8,223	36,931
At 31 December 2023	436,993	81,180	518,173
Carrying amount			
At 31 December 2023	998,396	4,012	1,002,408
At 31 December 2022	1,027,104	6,518	1,033,622

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

16 Fixed asset investments - Group

	Donated jewellery	Bank bonds	Shares in subsidiaries	Total
	£	£		£
Cost or valuation				
At 1 January 2023	6,100	311,026	-	317,126
Additions	-	311,371	-	311,371
	<u>6,100</u>	<u>622,397</u>	<u>-</u>	<u>628,497</u>
At 31 December 2023	6,100	622,397	-	628,497
Carrying amount				
At 31 December 2023	<u>6,100</u>	<u>622,397</u>	<u>-</u>	<u>628,497</u>
At 31 December 2022	<u>6,100</u>	<u>311,026</u>	<u>-</u>	<u>317,126</u>

Fixed asset investments - Charity

	Donated jewellery	Bank bonds	Shares in subsidiaries	Total
	£	£		£
Cost or valuation				
At 1 January 2023	6,100	311,026	2	317,128
Additions	-	311,371	-	311,371
	<u>6,100</u>	<u>622,397</u>	<u>2</u>	<u>628,499</u>
At 31 December 2023	6,100	622,397	2	628,499
Carrying amount				
At 31 December 2023	<u>6,100</u>	<u>622,397</u>	<u>2</u>	<u>628,499</u>
At 31 December 2022	<u>6,100</u>	<u>311,026</u>	<u>2</u>	<u>317,128</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 £622,397 in fixed business bonds, which are due to mature within less than one year. Of the £622,397 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 FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

17 Subsidiaries

Details of the charity's subsidiaries at 31 December 2023 are as follows:

Name of undertaking	Class of shares held	% Held
MPS Commercial Limited	Ordinary £1	100.00
Rare Disease Research Partners Limited	Ordinary £1	100.00

The aggregate capital and reserves and the result for the year of subsidiaries excluded from consolidation was as follows:

Name of undertaking	Profit/(Loss) £	Capital and Reserves £
MPS Commercial Limited	-	1
Rare disease Research Partners Limited	-	1

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.

18 Debtors - Group

	2023 £	2022 £
Amounts falling due within one year:		
Trade debtors	499,760	327,585
Other debtors	1,435	2,249
Prepayments and accrued income	39,073	38,718
	<u>540,268</u>	<u>368,552</u>

Debtors - Charity

	2023 £	2022 £
Amounts falling due within one year:		
Trade debtors	1,470	5,029
Amounts owed by group undertakings	240,386	432,465
Other debtors	1,435	1,988
Prepayments and accrued income	13,458	8,119
	<u>256,749</u>	<u>447,601</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

18 Debtors - Group

(Continued)

19 Creditors: amounts falling due within one year - Group

	2023	2022
	£	£
Other taxation and social security	30,403	-
Trade creditors	19,429	32,398
Other creditors	245,495	428,997
Accruals and deferred income	264,948	17,113
	<u>560,275</u>	<u>478,508</u>

Creditors: amounts falling due within one year Charity

	2023	2022
	£	£
Trade creditors	5,856	12,034
Other creditors	13,586	35,724
Accruals and deferred income	75,493	14,913
	<u>94,935</u>	<u>62,671</u>

Included within other creditors is deferred income of £253,178 (2022: £187,140). 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 2023.

20 Retirement benefit schemes

Defined contribution schemes

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

The charge to profit or loss in respect of defined contribution schemes was £59,156 (2022 - £52,195).

At 31 December 2023 the amounts outstanding were £6,510 (2022 £7,647).

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

21 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 January 2023	Incoming resources	Resources expended	At 31 December 2023
	£	£	£	£
MPS restricted fund	116,965	312,246	(352,283)	76,928
LSD restricted fund	11,270	11,150	(7,080)	15,340
Research restricted fund	109,377	500	-	109,877
	<u>237,612</u>	<u>323,896</u>	<u>(359,363)</u>	<u>202,145</u>
Previous year:	At 1 January 2022	Incoming resources	Resources expended	At 31 December 2022
	£	£	£	£
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
	<u>175,402</u>	<u>369,420</u>	<u>(307,210)</u>	<u>237,612</u>

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.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

22 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 January 2023	Incoming resources	Resources expended	At 31 December 2023
	£	£	£	£
General charitable fund	750,000	1,489,085	(1,489,085)	750,000
Property fund	1,027,103	-	(28,708)	998,395
Research fund	147,929	-	(50,755)	97,174
Service development fund	166,684	-	(68,448)	98,236
Building refurbishment fund	100,000	-	-	100,000
Christine Lavery memorial fund	100,000	-	-	100,000
	<u>2,291,716</u>	<u>1,489,085</u>	<u>(1,636,996)</u>	<u>2,143,805</u>
Previous year:	At 1 January 2022	Incoming resources	Resources expended	At 31 December 2022
	£	£	£	£
General charitable fund	750,000	1,351,823	(1,351,823)	750,000
Property fund	1,055,811	-	(28,708)	1,027,103
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>2,643,610</u>	<u>1,351,823</u>	<u>(1,703,717)</u>	<u>2,291,716</u>

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.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

23 Analysis of net assets between funds

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Fund balances at 31 December 2023 are represented by:			
Tangible assets	1,006,049	-	1,006,049
Investments	628,497	-	628,497
Current assets/(liabilities)	509,259	202,145	711,404
	<u>2,143,805</u>	<u>202,145</u>	<u>2,345,950</u>

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Fund balances at 31 December 2022 are represented by:			
Tangible assets	1,034,258	-	1,034,258
Investments	317,126	-	317,126
Current assets/(liabilities)	940,332	237,612	1,177,944
	<u>2,291,716</u>	<u>237,612</u>	<u>2,529,328</u>

24 Related party transactions

Transactions with related parties

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

24 Related party transactions

(Continued)

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 £240,386 (2022: £432,465). All the profits of MPS Commercial Limited for the period have been distributed by Gift Aid to the charity, these totalled £40,387 (2022: £232,465).

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 (2022: £200,000) on which interest of £13,000 (2022: £6,125) was charged.

During the year donations and pledges of £ (2022: £1,540) were received from trustees of the charity.

25 Cash generated from operations

	2023	2022
	£	£
Deficit for the year	(183,378)	(289,684)
Adjustments for:		
Investment income recognised in statement of financial activities	(50,720)	(33,866)
Depreciation and impairment of tangible fixed assets	34,474	34,141
Movements in working capital:		
(Increase) in debtors	(171,716)	(53,455)
Increase/(decrease) in creditors	81,767	(96,089)
Cash absorbed by operations	<u>(289,573)</u>	<u>(438,953)</u>

26 Analysis of changes in net funds

The charity had no material debt during the year.