

Charity registration number 1143472 (England and Wales)

Charity registration number SCO41012 (Scotland)

Company registration number 07726882

**SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**  
**ANNUAL REPORT AND CONSOLIDATED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2024**



**MPS Society**  
transforming lives through  
support, research & awareness

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## LEGAL AND ADMINISTRATIVE INFORMATION

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Trustees	Katy Brown Sarah Burgess Judith Evans Professor Simon Heales Professor Derralynn Hughes D M Patton Phillip Pearson Wilma Robins Fiona Stewart Dr G McKee Prof B G Winchester	(Appointed 26 January 2024)
Secretary	Toni Ellerton	
Senior management	Robert Stevens John Illankovan Sophie Thomas  Anna Featherstone Steve Cotterell  Toni Ellerton  Barbara Cotterell Helen Crawley	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
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 46 Hamilton Square Birkenhead Wirral Merseyside CH41 5AR	
Solicitors	Womble Bond Dickinson 4 More London Riverside London SE1 2AU	

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# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## CHAIRMAN'S STATEMENT

**FOR THE YEAR ENDED 31 DECEMBER 2024**

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This year was one of the most challenging in the MPS Society's history but as I reflect on how we dealt with those challenges, many of which could not have been envisaged, I can see so many new ideas which were generated and I feel proud of the diverse approach we have adopted to support our community as we react to their changing needs. As always, we continue to put our community at the centre of everything we do.


The exciting and very successful Fabry Matters Conference 2024 was a major highlight, collecting data and informing the patient community in a single productive weekend. This was a completely new approach to the way we run a conference, and proved extremely popular with the community, clinicians, pharma, and all who attended, and it will help to inform the way we organise future events.

We expanded the Facebook Support hub with the addition of WhatsApp based social hubs – these have really taken off under the guidance of the Support and Advocacy team. We now have support groups for our Fabry community, bereaved families and our young voices, alongside the support hub on Facebook. We are also running regular virtual coffee mornings for groups to get together and share experiences or just have a chat. But we also see the importance of continuing to offer face-to-face events and were able to offer plenty of activities for individuals and families alongside the online communities.

In March we launched the Weekly Lucky Lottery which was a new venture for fundraising. So far 90 people are playing, and we've had 37 winners. It was a record year for the London Marathon raising over £45,000, an incredible amount. We joined the Kind 2 Mind campaign during MPS Awareness Week and thanks to pledgers raised a super £28,000, and we also exceeded expectations for the Big Give Christmas Campaign raising a further £32,000.

It's been a busy year for our clinical advisory committee, CSAC. We are delighted that Professor Simon Jones and Dr David Whiteman have joined the committee, bringing their expertise to the team. We decided to put out a single call for grants, so we could assess all applications together. After careful consideration, we agreed to award grants to three applicants. As we had a smaller fund to award than in previous years, we needed to make sure we funded projects that will most benefit our members.

The MPS Society has always been an innovator in the rare disease community and as we look forward to 2025 and beyond, we will continue to carry out our vision and mission for the benefit of our community.

  
.....  
Judith Evans

**Chair of Trustees**

Date: 27/06/2025

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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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 2024.

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 governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" 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)".

#### 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, Geleophysic 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 2024

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### Achievements and performance

#### **Access to Exceptional Support and Advice Support and Advocacy Team**

Throughout 2024 our Support and Advocacy Team have been strengthening the offer to our member community. This has been through engagement, community groups and events and individual support and advocacy. The top three areas where the team have assisted the community were via emotional support, through attending an event and through help with benefits. Of those who provided feedback, 75.5% were satisfied or very satisfied with the support they received and 84.4% would seek support in the future.

In 2024 we welcomed 68 new members to the MPS Society who join for free and are given specialised practical and emotional support for their whole family.

### **Community groups**

We expanded the support hub from a private Facebook group to a series of community WhatsApp groups which include:

- **MPS Social Hub** – a group open to all our members (both affected and unaffected)
- **Fabry** – open to all our Fabry community as their needs can differ from the wider MPS community. We also offer a Fabry men's group.
- **Time to chat** – combines a weekly Zoom catch up and lively WhatsApp group for over 18s who are affected by MPS or a related condition.
- **Parents and carers** – we offer several active WhatsApp groups for mums, dads and those who have caring responsibilities which acts as a place to share, vent and find a shoulder to lean on.
- **Bereaved** – we offer opportunities for bereaved families to meet virtually throughout the year.
- **Scottish Families** – a regional group for members living in Scotland

Alongside our WhatsApp communities we now offer a range of virtual coffee mornings (via Teams). These include groups for parents and carers, our Fabry community and our bereaved community. These points of connection serve to increase community connection and provide tailored group education.

### **Membership and Community Engagement**

We want to ensure that everything we do aligns with the needs of our members. We do this by listening to our members, seeking feedback about existing services and providing opportunities for members to meaningfully engage with us and influence the direction of the services we provide.

Rare Voices, launched in 2024, is a member engagement forum hosted by the MPS Society Support and Advocacy Team. Our aim is for Rare Voices to include a representative group of affected adults, parents, carers, siblings and bereaved members. The purpose of the group is to provide representatives from the MPS Society membership with a forum to provide feedback, make suggestions and influence how the MPS provides services to our membership.

In 2025 we are adding an Ambassador Programme for affected adult members.

### **Mental health support**

We offer a range of virtual wellbeing support opportunities for our community to connect with peers and to access support to improve mental health and wellbeing, plus 1-to-1 counselling (in 2024 we provided 162 counselling sessions per year averaging 10 sessions per client).

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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### Support events

In 2024 we held nine events bringing more than 700 people together. We offer opportunities for affected children, young people and their parents to spend a day with people just like them and we reach out to our bereaved community to come together and share memories and experiences. Our events are also an excellent opportunity for our Advocacy & Support team to meet with members new and old in a casual setting.

Our families were unanimous in expressing the impact meeting other families and being able to share stories, tips, and support has on them and this shows in the feedback received following each of our events in 2024.

### Alton Towers family weekend - June

*"It was lovely to come as a family and meet new friends in the evening - also the price per person for the hotel and entrance tickets was amazing"*

### Newly diagnosed family get together - July

*"We'd also never met anyone with MPS conditions other than Hurlers so there were a lot of unknowns going into the day...we had the opportunity to chat to Bob for quite a while which we really valued and we have a good catch up with Sally in Advocacy too."*

### Legoland - August

*"Seeing the other MPS families and having the ride passes this time made such a difference to our day"*

### Weekend of remembrance - September

*"Beautiful way to still feel supported and part of the MPS society after losing our loved ones"*

### Independent Adult weekend - November

*"Getting together with people with my condition, chatting and having a laugh"*

### Fabry Matters 2024

In March 2024, the MPS Society organised a Fabry conference, bringing together patients, researchers, and clinicians for a weekend of connection and knowledge-sharing within the Fabry community. Insights were gathered during the event from Fabry patients and their caregivers through surveys and interactive post-it note boards, providing valuable perspectives on their experiences and needs. This was a new approach to data gathering which meant we could gain insights from an often over-surveyed community whilst offering knowledge in return. It provided information on symptom management, attitudes to research and clinical trials and an emotional map of the patient's Fabry journey.

# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

## **TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024**

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### **Access to World-Class Clinical Care Clinical Scientific Advisory Committee**

In 2024 our Clinical Scientific Advisory Committee (CSAC) paid out £81,934 in grants and committed a further £129,766 to fund future research. The committee were able to fully fund two grant applications. The first one focused on MPS III Sanfilippo and the other revolves around the blood brain barrier. In addition, they offered partial funding in the form of a 'challenge grant' for a project looking at lysosomal damage repair. We ran a virtual CSAC open day at the start of October which included: presentations about what a biomarker is and how we measure it by Kevin Mills, an update on Brian Bigger's research, a look at a study to improve the quality of life of adults with Fabry disease using exercise by Sarah Gosling and Dan Bailey as well as an overview of what is happening in Rare Disease Research Partners (RDRP) by Alex Morrison. CSAC also gave funds towards two projects that took part in the Dragon's Den style competition at the Fabry Matters 2024 conference. These were:

- Establishing Novel Retinal Vascular and Neural Biomarkers in Fabry Patients Using Optical Coherence Tomography Angiography (OCT-A) for Assessing the Role of Treatment in Retinal Blood Flow and retinal vascular density
- Understanding atrial arrhythmia in Fabry Disease – the development of patient-specific in silico atrial models

### **Access to Effective Treatments Representing you**

We continue to represent our patient community at expert meetings, events and committees throughout the year. This year included the WORLD Symposium in San Diego, USA and the 17th International Symposium on MPS and related diseases in Würzburg, Germany where we hosted an MPS airways meeting. Our staff have also represented us at international expert meetings, including Fabry International Network (FIN) meeting, International MPS and Related Diseases Network (IMPSN) board meeting, Aspire Biosciences meeting and the Patient Advisory Group (PAG) meeting. We also attended meetings that focused on treatment and diagnosis, including the NICE Voluntary and Community Sector (VCS) forum meeting, NICE Highly Specialised Technologies (HST) meeting, MLD newborn screening steering group and LSD collaborative. Our support team headed out to represent us at the Council for Disabled Children, which was primarily focused on special educational needs and disabilities (SEND), and at Community Care Live Conference which concentrated on 'solution focused practice' to help people move towards the future that they want and to learn what can be done differently by using their existing skills, strategies and ideas, rather than focusing on the problem.

### **Clinical liaisons**

Our head of patient services and clinical liaison has worked with colleagues to further the goals of the charity in delivering appropriate treatment and clinical care. Some highlights include:

- Responding to NICE's three-year strategy for involvement and engagement
- Meeting with metabolic teams to aid cardiac specification plans including patient information leaflets and training meetings
- Implementing a pathway for LSD Transitions
- Launched PPPN (Patient, Professional, Partnership Network) with a focus on clinical guideline development and LSD patient community survey
- Responded to NICE's consultation on methods and processes for including NICE technology appraisal recommendations in guidelines
- Shared information with our LAL D community about the discontinuation of the appraisal for people with late onset/non Wolmans form of the condition
- Received approval by Scottish Medicines Consortium (SMC) for pegunigalsidase alfa (ERT for Fabry) for use in adults
- Following a successful launch in November 2023 of the MPS airway project (MAP), we welcomed 24 attendees, representing six countries, to the first hybrid meeting in April 2024 in Würzburg Germany to discuss complex airways with a focus on MPS II and MPS IVA. Proposed actions include development of international consensus guidelines, development of an emergency airway management plan for patients and discussion on the pathophysiology of the airways and trachea in MPS II and IVA.
- Generation Study – MPS were approached to review proposed family information sheets for the MPS conditions included in the study. Our amendments and suggestions were accepted.
- All Wales Medicines Strategy Group approved Naglazyme for use in Wales to treat MPS VI Maroteaux-Lamy.



# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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### **Operating effective processes**

To carry out our work we rely on fundraising and donations. 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 highlights**

#### **Individual donations**

We are very grateful to our supporters who continue to donate to us regularly. In 2024, we received £22,000 from regular donations and payroll giving schemes. We also received over £10,000 from donations and tributes in memory of loved ones and over £7,000 in one-off donations.

#### **Events and challenges**

We are pleased to have raised over £87,000 from challenge events in 2024. This included a record year for the London Marathon which raised £45,000.

#### **Christmas Campaign**

This year was our best ever Big Give Christmas Challenge raising over £32,000 for our community events.

#### **MPS Awareness Week**

Our fundraising target was smashed this year and raised over £28,000. This was generated from a variety of events including our Kind2Mind appeal, schools, nurseries and specialist centres taking part in Wear it Blue, cake sales and coffee mornings, a pub quiz, a golf day, a football presentation, a half marathon, some online fundraisers and donations from some very kind individuals and companies.

#### **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 2024 include National Lottery Awards for All, Sir James Knott Trust, James Tudor Foundation, Stafford Trust, Wixamtree Trust, The Big Give Trust, Charles & Elspeth Thomas Charitable Trust, Sisters of the Holy Cross Charitable Trust, The W E Dunn Charitable Trust, D'Oyly Carte Charitable Trust, Geoff and Fiona Squire Foundation, Annie Tranmer Charitable Trust, Ardwick Trust, Sir James Reckitt Charity, Clover Trust, Frazer Trust (AKA Joseph Strong Frazer Trust), Himat Tanna Charitable Trust, Enkalon Foundation, The John Coates Charitable Trust, Zochonis Charitable Trust, Roland Callingham Foundation, Adint Charitable Trust, Carrington Charitable Trust, Baddiley Consolidated Charities, The Camelia Trust, Hugh Fraser Foundation, Pilkington Charitable Trust, Bowen Lodge Freemasons, Normanby Charitable Trust, John Avins Trust, Sahdra Charitable Trust, Constance Travis Charitable Trust, Theodore Maxxy Foundation, Sovereign Health Care and Mersey Lodge Freemasons.

We were very grateful to have received financial contributions during 2024 from pharmaceutical companies towards various aspects of our patient support services and projects. Sanofi, Chiesi, Amicus Therapeutics, Takeda UK, PHARMExcel, BioMarin, JCR Pharmaceuticals, REGENXBIO, Denali and Orchard Therapeutics have provided funding to MPS Society in support of 2024 patient projects but have had no input into content or output. Ultragenyx have provided unrestricted funding to MPS Society in support of 2024 patient projects.

Our grants and donations from charitable trusts and foundations came to £229,327; funds from pharmaceutical companies came to £288,000; and grants from other sources came to £22,346; giving a total of £539,673 from these sources.

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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### *Fundraising performance*

#### **Staff development and support**

Our staff are a core part of our charity and embracing their knowledge, skills and expertise helps shape the organisation to be the best it can be. We use our annual survey to spot check where we are as an employer and were delighted that in 2024 most of our staff (95%+) either agreed or strongly agreed in key areas. We continue to invest in our staff, upskilling and offering training opportunities. We encourage our staff to share their knowledge through bitesize training sessions and in 2024 invested £5.5k on external courses to refresh safeguarding and support development. Some staff satisfaction highlights:

For several years we have offered our staff a 24/7 employee assistance programme to support them if they are experiencing difficult times. To further enhance our offering we have in 2024 put 2 team members through a registered Mental Health First Aider course to provide that extra care and guidance. We plan to increase this by a further 2 team members during 2025.

#### **Governance**

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.

#### **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 £751,504 in comparison to £602,741 in 2023. Receipts from donations £242,514 compared with £68,062 in 2023. This year legacies of £1,039 were received whereas £133,228 of legacies were received in 2023.

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 2024, MPS Commercial were able to donate £150,539 (2023: £40,387) 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 2024 was £1,934,735 (2023: £1,812,981) compared with total expenditure of £1,862,072 (2023: £1,996,359) resulting in a surplus of £72,663 (2023: deficit £183,378).

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 DIRECTORS' REPORT) (CONTINUED)** **FOR THE YEAR ENDED 31 DECEMBER 2024**

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### **Reserves policy**

In the year, ending 31 December 2024 the trustees reviewed the charity's reserves policy to ensure that it is flexible enough to withstand the highs 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 £635,883 (2023: £730,696). The level of free reserves as at 31 December 2024 amounted to £743,102 (2023: £742,346) which amounts to 7 months of overall expenditure of the Society.

### **Plans for future periods**

Our focus in 2024 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.

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

(Resigned 27 April 2024)

Professor Simon Heales

Professor Derralynn Hughes

D M Patton

Phillip Pearson

Wilma Robins

Fiona Stewart

Dr G McKee

(Appointed 26 January 2024)

Prof B G Winchester

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

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

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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### *Organisational structure*

#### **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 2024

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### *Other matters*

#### **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 2024

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### 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: 27/06/2025

# **SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

## **STATEMENT OF TRUSTEES' RESPONSIBILITIES**

***FOR THE YEAR ENDED 31 DECEMBER 2024***

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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. 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 OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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#### Opinion

We have audited the financial statements of Society for Mucopolysaccharide Diseases (the 'charity') and its subsidiary for the year ended 31 December 2024 which comprise the consolidated statement of financial activities, the consolidated and charity balance sheet, the consolidated 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 charitable company's affairs as at 31 December 2024 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.

#### 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 OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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#### **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 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 OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES**

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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 charitable company's trustees, as a body, in accordance with 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 FCCA (Senior Statutory Auditor)**

For and on behalf of Xeinadin Audit Limited, Statutory Auditor

Chartered Accountants

46 Hamilton Square

Birkenhead

Wirral

Merseyside

CH41 5AR

Date: 11.7.25

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 DECEMBER 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
<b>Income from:</b>							
Donations and legacies	4	243,553	-	243,553	201,290	-	201,290
<u>Charitable activities</u>							
Advocacy support	5	286,727	425,665	712,392	278,845	247,396	526,241
Psychological support	5	-	15,000	15,000	-	15,000	15,000
MPS awareness	5	-	-	-	-	20,000	20,000
Family support and special events	5	-	24,112	24,112	-	41,500	41,500
Other trading activities	6	864,051	-	864,051	958,230	-	958,230
Investments	7	75,627	-	75,627	50,720	-	50,720
<b>Total income</b>		<b>1,469,958</b>	<b>464,777</b>	<b>1,934,735</b>	<b>1,489,085</b>	<b>323,896</b>	<b>1,812,981</b>
<b>Expenditure on:</b>							
<u>Raising funds</u>							
Fundraising and publicity	8	170,260	-	170,260	158,534	-	158,534
Commercial trading activity	8	456,391	-	456,391	612,973	-	612,973
		<b>626,651</b>	<b>-</b>	<b>626,651</b>	<b>771,507</b>	<b>-</b>	<b>771,507</b>
<u>Charitable activities</u>							
Advocacy services & member events	9	244,568	502,002	746,570	355,289	359,363	714,652
Awareness raising	9	176,451	-	176,451	184,522	-	184,522
Trading activities - Patients support	9	230,466	-	230,466	274,923	-	274,923
Research grants	9	81,934	-	81,934	50,755	-	50,755
<b>Total charitable expenditure</b>		<b>733,419</b>	<b>502,002</b>	<b>1,235,421</b>	<b>865,489</b>	<b>359,363</b>	<b>1,224,852</b>
<b>Total expenditure</b>		<b>1,360,070</b>	<b>502,002</b>	<b>1,862,072</b>	<b>1,636,996</b>	<b>359,363</b>	<b>1,996,359</b>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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

**FOR THE YEAR ENDED 31 DECEMBER 2024**

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Notes						
Net income/(expenditure) and movement in funds	109,888	(37,225)	72,663	(147,911)	(35,467)	(183,378)
<b>Reconciliation of funds:</b>						
Fund balances at 1 January 2024	2,143,805	202,145	2,345,950	2,291,716	237,612	2,529,328
<b>Fund balances at 31 December 2024</b>	<u>2,253,693</u>	<u>164,920</u>	<u>2,418,613</u>	<u>2,143,805</u>	<u>202,145</u>	<u>2,345,950</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 2024

	Notes	2024 £	£	2023 £	£
<b>Fixed assets</b>					
Tangible assets	17		976,585		1,006,049
Investments	18		859,525		628,497
			<u>1,836,110</u>		<u>1,634,546</u>
<b>Current assets</b>					
Debtors	20	337,461		540,268	
Cash at bank and in hand		1,183,776		731,411	
		<u>1,521,237</u>		<u>1,271,679</u>	
<b>Creditors: amounts falling due within one year</b>	21	(938,734)		(560,275)	
<b>Net current assets</b>			<u>582,503</u>		<u>711,404</u>
<b>Total assets less current liabilities</b>			<u><u>2,418,613</u></u>		<u><u>2,345,950</u></u>
<b>The funds of the charity</b>					
Restricted income funds	23	164,920		202,145	
Unrestricted funds	24	2,253,693		2,143,805	
		<u>2,418,613</u>		<u>2,345,950</u>	

The financial statements were approved by the trustees on 27/06/2025



Judith Evans  
Trustee

Company registration number 07726882 (England and Wales)

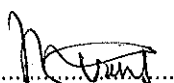
# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## CHARITABLE COMPANY BALANCE SHEET

AS AT 31 DECEMBER 2024

	Notes	2024 £	£	2023 £	£
<b>Fixed assets</b>					
Tangible assets	17		973,851		1,002,408
Investments	18		859,527		628,499
			<u>1,833,378</u>		<u>1,630,907</u>
<b>Current assets</b>					
Debtors	20	288,959		256,749	
Cash at bank and in hand		546,001		553,229	
		<u>834,960</u>		<u>809,978</u>	
<b>Creditors: amounts falling due within one year</b>	21	(249,725)		(94,935)	
<b>Net current assets</b>			<u>585,235</u>		<u>715,043</u>
<b>Total assets less current liabilities</b>			<u>2,418,613</u>		<u>2,345,950</u>
<b>The funds of the charity</b>					
Restricted income funds	23		164,920		202,145
Unrestricted funds	24		2,253,693		2,143,805
			<u>2,418,613</u>		<u>2,345,950</u>

The financial statements were approved by the trustees on .....27/06/2025-



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 2024

	Notes	2024 £	£	2023 £	£
<b>Cash flows from operating activities</b>					
Cash generated from/(absorbed by) operations	27		612,426		(289,575)
<b>Investing activities</b>					
Purchase of tangible fixed assets		(4,660)		(6,263)	
Proceeds from disposal of investments		(231,028)		(311,371)	
Investment income received		75,627		50,720	
<b>Net cash used in investing activities</b>			(160,061)		(266,914)
<b>Net cash generated from financing activities</b>			-		-
<b>Net increase/(decrease) in cash and cash equivalents</b>			452,365		(556,489)
Cash and cash equivalents at beginning of year			731,411		1,287,900
<b>Cash and cash equivalents at end of year</b>			1,183,776		731,411

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS

### FOR THE YEAR ENDED 31 DECEMBER 2024

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#### 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.

##### 1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" 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)". 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 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 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.

##### 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.



# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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### 1 Accounting policies

(Continued)

#### 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.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

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.

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 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 2024

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#### 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 2024**

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### **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 2024 £	Unrestricted funds 2023 £
Donations and gifts	242,514	68,062
Legacies	1,039	133,228
	<u>243,553</u>	<u>201,290</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 5 Income from charitable activities

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
<b>Advocacy support</b>						
Grants receivable	286,727	319,730	606,457	278,845	169,800	448,645
National Lottery community funds	-	105,935	105,935	-	77,596	77,596
<b>Psychological support</b>						
Grants receivable	-	15,000	15,000	-	15,000	15,000
<b>MPS awareness</b>						
Grants receivable	-	-	-	-	20,000	20,000
<b>Family support and special events</b>						
Grants receivable	-	24,112	24,112	-	41,500	41,500
	<u>286,727</u>	<u>464,777</u>	<u>751,504</u>	<u>278,845</u>	<u>323,896</u>	<u>602,741</u>

### 6 Income from other trading activities

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Survey income in subsidiary	317,546	479,497
Management fees in subsidiary	546,505	478,733
Other trading activities	<u>864,051</u>	<u>958,230</u>

### 7 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Rental income	29,917	29,917
Interest receivable	45,710	20,803
	<u>75,627</u>	<u>50,720</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 8 Expenditure on raising funds

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
<b>Fundraising and publicity</b>		
Grant consultancy costs	4,337	6,026
Fundraising expenses	14,626	15,475
Staff costs	108,697	105,747
Depreciation and impairment	6,370	6,404
Support costs	36,230	24,882
	<u>170,260</u>	<u>158,534</u>
<b>Trading costs</b>		
Survey costs	68,953	41,936
Staff costs	345,699	412,384
Depreciation and impairment	2,276	2,456
Support costs	39,463	156,197
	<u>456,391</u>	<u>612,973</u>
<b>Total costs</b>	<u><u>626,651</u></u>	<u><u>771,507</u></u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 9 Expenditure on charitable activities

	Advocacy services & member events	Awareness raising	Trading activities - Patients support	Research grants	Total
	2024	2024	2024	2024	2024
	£	£	£	£	£
<b>Direct costs</b>					
Staff costs	395,134	101,710	230,466	-	727,310
Depreciation and impairment	15,924	4,777	-	-	20,701
Communication	140,403	-	-	-	140,403
Communication	7,033	3,659	-	-	10,692
MPS awareness	-	10,216	-	-	10,216
Donations and tributes in memory	1,079	-	-	-	1,079
Patient welfare gifts	33	-	-	-	33
	<u>559,606</u>	<u>120,362</u>	<u>230,466</u>	<u>-</u>	<u>910,434</u>
Grant funding of activities (see note 10)	-	-	-	81,934	81,934
<b>Share of support and governance costs (see note 11)</b>					
Support	85,094	25,528	-	-	110,622
Governance	101,870	30,561	-	-	132,431
	<u>746,570</u>	<u>176,451</u>	<u>230,466</u>	<u>81,934</u>	<u>1,235,421</u>
<b>Analysis by fund</b>					
Unrestricted funds	244,568	176,451	230,466	81,934	733,419
Restricted funds	502,002	-	-	-	502,002
	<u>746,570</u>	<u>176,451</u>	<u>230,466</u>	<u>81,934</u>	<u>1,235,421</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 9 Expenditure on charitable activities

(Continued)

Previous year:	Advocacy services & member events	Awareness raising	Trading activities - Patients support	Research grants	Total
	2023	2023	2023	2023	2023
	£	£	£	£	£
<b>Direct costs</b>					
Staff costs	412,202	118,862	274,923	-	805,987
Depreciation and impairment	16,009	4,802	-	-	20,811
Communication	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>
Grant funding of activities (see note 10)	-	-	-	50,755	50,755
<b>Share of support and governance costs (see note 11)</b>					
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>
<b>Analysis by fund</b>					
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>

### 10 Grants payable

In 2024, 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.

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# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 11 Support costs allocated to activities

	2024 £	2023 £
Recruitment and training costs	6,067	8,559
General office expenses	88,100	62,072
Insurance	14,352	13,895
Subscriptions	2,634	2,472
Staff welfare	14,098	14,875
Computer expenses	30,882	32,764
Bank charges	2,861	5,149
Bad debts	-	100,000
Travel and subsistence	17,882	11,988
Consultancy expenses	7,129	20,163
Governance costs	134,741	104,914
	<u>318,746</u>	<u>376,851</u>
<b>Analysed between:</b>		
Fundraising	75,693	181,079
Advocacy services & member events	186,964	150,594
Awareness raising	56,089	45,178
	<u>318,746</u>	<u>376,851</u>

	2024 £	2023 £
<b>Governance costs comprise:</b>		
Staff costs	56,247	54,873
Depreciation	4,777	4,803
Audit fees	9,438	8,353
Legal and professional	3,923	6,193
Management costs	60,356	30,692
	<u>134,741</u>	<u>104,914</u>

### 12 Net movement in funds

	2024 £	2023 £
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	9,438	8,353
Depreciation of owned tangible fixed assets	34,124	34,475
	<u></u>	<u></u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

### 13 Employees

The average monthly number of employees during the year was:

	2024 Number	2023 Number
Chief executives	1	2
Administration	4	5
Advice, information & support	14	16
Commercial trading operations	13	14
Total	32	37

Employment costs	2024 £	2023 £
Wages and salaries	1,082,478	1,215,268
Social security costs	104,393	104,567
Other pension costs	51,082	59,156
	1,237,953	1,378,991

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

	2024 Number	2023 Number
£90,001 - £100,000	1	1
£100,001 - £110,000	-	1

### Remuneration of key management personnel

The key management personnel of the group, comprise the trustees, the group chief executive officer, head of patient services, head of fundraising and head of finance. The total employee benefits of the key management personnel were £285,063 (2023: £334,300). The highest paid employee of the charity and the group had accrued £5,769 (2023: £5,769) in employer pension contributions.

### 14 Taxation

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

### 15 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 2024 these totalled £9,432 (2023: £2,321) for all trustees.

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

#### 16 MPS Commercial Limited

The subsidiary, MPS Commercial Limited, had incoming resources of £911,722 (2023 £958,205) and outgoing resources of £761,232 (2023 £917,818) leaving a surplus of £150,539 (2023 £40,357) which was gifted to the Society for Mucopolysaccharide Diseases.

#### 17 Tangible Fixed Assets - Group

	Freehold land and buildings £	Computers and equipment £	Total £
<b>Cost</b>			
At 1 January 2024	1,435,389	76,401	1,511,790
Additions	-	4,660	4,660
At 31 December 2024	1,435,389	81,061	1,516,450
<b>Depreciation and impairment</b>			
At 1 January 2024	436,993	68,748	505,741
Depreciation charged in the year	28,708	5,416	34,124
At 31 December 2024	465,701	74,163	539,864
<b>Carrying amount</b>			
At 31 December 2024	969,687	6,898	976,585
At 31 December 2023	998,396	7,653	1,006,049

#### Tangible Fixed Assets - Charity

	Freehold land and buildings £	Computers and equipment £	Total £
<b>Cost</b>			
At 1 January 2024	1,435,389	60,328	1,495,717
Additions	-	4,660	4,660
At 31 December 2024	1,435,388	64,988	1,516,449
<b>Depreciation and impairment</b>			
At 1 January 2024	436,993	56,315	493,308
Depreciation charged in the year	28,708	3,140	31,848
At 31 December 2024	465,701	59,455	525,156
<b>Carrying amount</b>			
At 31 December 2024	969,687	4,163	973,850
At 31 December 2023	998,396	4,012	1,002,408

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

#### 18 Fixed asset investments - Group

	Donated jewellery £	Bank bonds £	Shares in subsidiaries £	Total £
<b>Cost or valuation</b>				
At 1 January 2024 & 31 December 2024	6,100	622,397	-	628,497
<b>Carrying amount</b>				
At 31 December 2024	6,100	622,397	-	628,497
At 31 December 2023	6,100	622,397	-	628,497

#### Fixed asset investments - Charity

	Donated jewellery £	Bank bonds £	Shares in subsidiaries £	Total £
<b>Cost or valuation</b>				
At 1 January 2024 & 31 December 2024	6,100	622,397	2	628,499
<b>Carrying amount</b>				
At 31 December 2024	6,100	622,397	2	628,499
At 31 December 2023	6,100	622,397	2	628,499

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 2024

### 19 Subsidiaries

Details of the charity's subsidiaries at 31 December 2024 are as follows:

Name of undertaking	Class of shares held	% Held	
		Direct	Indirect
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 Reserve s
	£	£
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.

### 20 Debtors - Group

	2024	2023
Amounts falling due within one year:	£	£
Trade debtors	276,939	499,760
Other debtors	641	1,435
Prepayments and accrued income	59,881	39,073
	<u>337,461</u>	<u>540,268</u>

#### Debtors - Charity

	2024	2023
Amounts falling due within one year:	£	£
Trade debtors	15,601	1,470
Amounts owed by group undertakings	250,539	240,386
Other debtors	24	1,435
Prepayments and accrued income	22,795	13,458
	<u>288,959</u>	<u>256,749</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

#### 21 Creditors: amounts falling due within one year - Group

	2024 £	2023 £
Other taxation and social security	23,202	30,403
Trade creditors	27,892	19,429
Other creditors	411,369	245,495
Accruals and deferred income	476,271	264,948
	<u>938,734</u>	<u>560,275</u>

#### Creditors: amounts falling due within one year - Charity

	2024 £	2023 £
Trade creditors	6,362	5,856
Other creditors	14,236	13,586
Accruals and deferred income	229,127	75,493
	<u>249,725</u>	<u>94,935</u>

Included within other creditors is deferred income of £466,334 (2023: £253,178). 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 2023 has been subsequently recognised as income in 2024.

#### 22 Retirement benefit schemes

	2024 £	2023 £
<b>Defined contribution schemes</b>		
Charge to profit or loss in respect of defined contribution schemes	<u>51,082</u>	<u>59,156</u>

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.

At 31 December 2024 the amounts outstanding were £7,055 (2023 £6,510).

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

#### 23 Restricted funds - Group and Charity

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 2024	Incoming resources	Resources expended	At 31 December 2024
	£	£	£	£
MPS restricted fund	76,928	464,777	(496,149)	45,556
LSD restricted fund	15,340	-	(5,853)	9,487
Research restricted fund	109,877	-	-	109,877
	<u>202,145</u>	<u>464,777</u>	<u>(502,002)</u>	<u>164,920</u>
	<u><u>202,145</u></u>	<u><u>464,777</u></u>	<u><u>(502,002)</u></u>	<u><u>164,920</u></u>
<b>Previous year:</b>	<b>At 1 January 2023</b>	<b>Incoming resources</b>	<b>Resources expended</b>	<b>At 31 December 2023</b>
	£	£	£	£
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>
	<u><u>237,612</u></u>	<u><u>323,896</u></u>	<u><u>(359,363)</u></u>	<u><u>202,145</u></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 2024

#### 24 Unrestricted funds - Group

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 2024	Incoming resources	Resources expended	Transfers	At 31 December 2024
	£	£	£	£	£
Generable charitable fund	750,000	1,380,262	(1,214,928)	(165,334)	750,000
Property fund	998,395	-	(28,708)	-	969,687
Research fund	97,174	89,696	(81,934)	-	104,936
Service development fund	98,236	-	-	165,334	263,570
Building refurbishment fund	100,000	-	(34,500)	-	65,500
Christine Lavery memorial fund	100,000	-	-	-	100,000
	<u>2,143,805</u>	<u>1,469,958</u>	<u>(1,360,070)</u>	<u>-</u>	<u>2,253,693</u>
Previous year:	At 1 January 2023	Incoming resources	Resources expended	Transfers	At 31 December 2023
	£	£	£	£	£
Generable 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>-</u>	<u>2,143,805</u>
	<u>2,291,716</u>	<u>1,489,085</u>	<u>(1,636,996)</u>	<u>-</u>	<u>2,143,805</u>



# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 24 Unrestricted funds - Group (Continued)

#### 24 Unrestricted funds - Charity

	At 1 January 2024	Incoming resources	Resources expended	Transfers	At 31 December 2024
	£	£	£	£	£
Generable charitable fund	750,000	603,709	(438,375)	(165,334)	750,000
Property fund	998,395	-	(28,708)	-	969,687
Research fund	97,174	89,696	(81,934)	-	104,936
Service development fund	98,236	-	-	165,334	263,570
Building refurbishment fund	100,000	-	(34,500)	-	65,500
Christine Lavery memorial fund	100,000	-	-	-	100,000
General funds	-	-	-	-	-
	<u>2,143,805</u>	<u>693,405</u>	<u>(583,517)</u>	<u>-</u>	<u>2,253,693</u>

Previous year:	At 1 January 2023	Incoming resources	Resources expended	Transfers	At 31 December 2023
	£	£	£	£	£
Generable charitable fund	750,000	925,085	(925,085)	-	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
General funds	-	-	-	-	-
	<u>2,291,716</u>	<u>925,085</u>	<u>(1,072,996)</u>	<u>-</u>	<u>2,143,805</u>
	<u>2,291,716</u>	<u>925,085</u>	<u>(1,072,996)</u>	<u>-</u>	<u>2,143,805</u>

### 25 Analysis of net assets between funds

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
At 31 December 2024:			
Tangible assets	976,585	-	976,585
Investments	859,525	-	859,525
Current assets/(liabilities)	417,583	164,920	582,503
	<u>2,253,693</u>	<u>164,920</u>	<u>2,418,613</u>

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 25 Analysis of net assets between funds

(Continued)

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
<b>At 31 December 2023:</b>			
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>

### 26 Related party transactions

#### Transactions with related parties

During the year the charity entered into the following transactions with related parties:

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 £250,539 (2023: £240,386). All the profits of MPS Commercial Limited for the period have been distributed by Gift Aid to the charity, these totalled £150,539 (2023: £40,387).

Rent and recharges of £34,375 (2023: £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 (2023: £200,000) on which interest of £14,375 (2023: £13,000) was charged.

# SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

27	Cash generated from/(absorbed by) operations	2024 £	2023 £
	Surplus/(deficit) for the year	72,663	(183,378)
	<b>Adjustments for:</b>		
	Investment income recognised in statement of financial activities	(75,627)	(50,720)
	Depreciation and impairment of tangible fixed assets	34,124	34,474
	<b>Movements in working capital:</b>		
	Decrease/(increase) in debtors	202,807	(171,716)
	Increase in creditors	378,459	81,767
	<b>Cash generated from/(absorbed by) operations</b>	<u>612,426</u>	<u>(289,573)</u>

## 28 Analysis of changes in net funds

The charity had no material debt during the year.