THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

England & Wales · Charity number 1143472

Details

Other names	WICKED GENES, MPS SOCIETY
Status	Registered
Legal form	Charitable company
Company number	07726882
Registered	2011-08-19
Register	View on the Charity Commission register

Contact

Address	Mps House Repton Place White Lion Road Amersham HP7 9LP
Phone	07867596494
Email	mps@mpssociety.org.uk
Website	www.mpssociety.org.uk

Activities

Objects: 1. THE RELIEF OF PERSONS SUFFERING FROM MUCOPOLYSACCHARIDE AND RELATED LYSOSOMAL DISEASES; AND2. TO ADVANCE MEDICAL RESEARCH INTO THE CAUSE, CURE, PREVENTION OR RELIEF OF SUCH DISEASES AND RELATED PAEDIATRIC NEURODEGENERATIVE BRAIN DISEASES PROVIDED THAT THE USEFUL RESULTS OF THE RESEARCH SHALL BE PUBLISHED.

Activities: THIS IS THE INCORPORATED SUCCESSOR CHARITY TO CHARITY NUMBER 287034, WHICH IS ITS UNINCORPORATED PREDECESSOR.The MPS Society is the only registered UK charity providing professional support to individuals, families and professionals affected by MPS and related diseases throughout the UK.

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Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£1,934,735	£1,862,072	£2,418,613	32
2023-12-31	£1,812,981	£1,996,359	£2,345,950	34
2022-12-31	£1,721,243	£2,010,927	£2,529,328	34
2021-12-31	£1,443,246	£1,581,251	£2,819,012	33
2020-12-31	£2,055,446	£1,513,142	£2,414,713	30

Trustees

Name	Role	Appointed
DAVID MAURICE PATTON		2017-12-02
Dr FIONA JANE STEWART		2020-04-04
Dr GLENN McKee		2024-01-26
JUDITH EVANS		2011-08-16
Katy Joanne Brown		2020-11-28
PROFESSOR BRYAN WINCHESTER		2011-08-16
PROFESSOR DERRALYNN ARLENE HUGHES		2022-11-26
PROFESSOR SIMON JAMES ROBERT HEALES		2022-11-26
Philip John Pearson		2019-02-15
SARAH BURGESS		2019-06-28
WILMA ROBINS		2011-08-19

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THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

England & Wales - Charity number 1143472

Accounts

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

xeinadin

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

LEGAL AND ADMINISTRATIVE INFORMATION

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	(Appointed 26 January 2024)
	Prof B G Winchester	
Secretary	Toni Ellerton	
Senior management	Robert Stevens	Group Chief Executive
	John Illankovan	Head of Group Finance
	Sophie Thomas	Senior Head of Patient Services and Clinical Liaisons
	Anna Featherstone	Head of Fundraising
	Steve Cotterell	Head of Support and Advocacy
	Toni Ellerton	Executive Assistant and Company Secretary
	Barbara Cotterell	HR Lead
	Helen Crawley	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	

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CHAIRMAN'S STATEMENT

FOR THE YEAR ENDED 31 DECEMBER 2024

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

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, Geleo Physic Dysplasia, GM-1 Gangliosidosis, Lysosomal Acid Lipase Deficiency (LAL D), Alpha-Mannosidosis, Beta-Mannosidosis, MSD Multiple sulphatase deficiency, Metachromatic Leukodystrophy, ML I Neuramidase Deficiency, ML II i-cell disease, ML III Pseudo Hurler Polydystrophy, ML IV, Sialic Acid Storage Disease, Winchester, Gaucher and Farber disease.

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).

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.

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 Wurzburg Germany to discuss complex airways with a focus on MPS II and MPSIVA. 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.

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.

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.

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.

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.

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.

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

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

Opinion

We have audited the financial statements of Society for Mucopolysaccharide Diseases (the 'charity') and it's 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.

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS 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 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.

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS 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 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 £
Income from:							
Donations and legacies	4	243,553	-	243,553	201,290	-	201,290
Charitable activities							-
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
Total income		1,469,958	464,777	1,934,735	1,489,085	323,896	1,812,981
Expenditure on:							
Raising funds							
Fundraising and publicity	8	170,260	-	170,260	158,534	-	158,534
Commercial trading activity	8	456,391	-	456,391	612,973	-	612,973
		626,651	-	626,651	771,507	-	771,507
Charitable activities							
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
Total charitable expenditure		733,419	502,002	1,235,421	865,489	359,363	1,224,852
Total expenditure		1,360,070	502,002	1,862,072	1,636,996	359,363	1,996,359

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) 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 £
Net income/(expenditure) and movement in funds		109,888	(37,225)	72,663	(147,911)	(35,467)	(183,378)
Reconciliation of funds:							
Fund balances at 1 January 2024		2,143,805	202,145	2,345,950	2,291,716	237,612	2,529,328
Fund balances at 31 December 2024		2,253,693	164,920	2,418,613	2,143,805	202,145	2,345,950

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

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

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 £	2024 £	2023 £	2023 £
Cash flows from operating activities					
Cash generated from/(absorbed by) operations	27		612,426		(289,575)
Investing activities					
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	
Net cash used in investing activities			(160,061)		(266,914)
Net cash generated from financing activities			-		-
Net increase/(decrease) in cash and cash equivalents			452,365		(556,489)
Cash and cash equivalents at beginning of year			731,411		1,287,900
Cash and cash equivalents at end of year			1,183,776		731,411

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.

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.

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.

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.

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
	243,553	201,290

5 Income from charitable activities

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Advocacy support						
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
Psychological support						
Grants receivable	-	15,000	15,000	-	15,000	15,000
MPS awareness						
Grants receivable	-	-	-	-	20,000	20,000
Family support and special events						
Grants receivable	-	24,112	24,112	-	41,500	41,500
	286,727	464,777	751,504	278,845	323,896	602,741

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	864,051	958,230

7 Income from investments

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

8 Expenditure on raising funds

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Fundraising and publicity		
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
	170,260	158,534
Trading costs		
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
	456,391	612,973
Total costs	626,651	771,507

9 Expenditure on charitable activities

	Advocacy services & member events	Awareness raising	Trading activities - Patients support	Research grants	Total
	2024	2024	2024	2024	2024
	£	£	£	£	£
Direct costs					
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
	559,606	120,362	230,466	-	910,434
Grant funding of activities (see note 10)	-	-	-	81,934	81,934
Share of support and governance costs (see note 11)					
Support	85,094	25,528	-	-	110,622
Governance	101,870	30,561	-	-	132,431
	746,570	176,451	230,466	81,934	1,235,421
Analysis by fund					
Unrestricted funds	244,568	176,451	230,466	81,934	733,419
Restricted funds	502,002	-	-	-	502,002
	746,570	176,451	230,466	81,934	1,235,421

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
	£	£	£	£	£
Direct costs					
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
	564,058	139,344	274,923	-	978,325
Grant funding of activities (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
	714,652	184,522	274,923	50,755	1,224,852
Analysis by fund					
Unrestricted funds	355,289	184,522	274,923	50,755	865,489
Restricted funds	359,363	-	-	-	359,363
	714,652	184,522	274,923	50,755	1,224,852

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.

-

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 subsistance	17,882	11,988
Consultancy expenses	7,129	20,163
Governance costs	134,741	104,914
	318,746	376,851
Analysed between:		
Fundraising	75,693	181,079
Advocacy services & member events	186,964	150,594
Awareness raising	56,089	45,178
	318,746	376,851

	2024	2023
Governance costs comprise:	£	£
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
	134,741	104,914

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

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.

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
	£	£	£
Cost			
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
Depreciation and impairment			
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
Carrying amount			
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
	£	£	£
Cost			
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
Depreciation and impairment			
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
Carrying amount			
At 31 December 2024	969,687	4,163	973,850
At 31 December 2023	998,396	4,012	1,002,408

18 Fixed asset investments - Group

	Donated jewellery	Bank bonds	Shares in subsidiaries	Total
	£	£	£	£
Cost or valuation				
At 1 January 2024 & 31 December 2024	6,100	622,397	-	628,497
Carrying amount				
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
	£	£	£	£
Cost or valuation				
At 1 January 2024 & 31 December 2024	6,100	622,397	2	628,499
Carrying amount				
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.

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 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.

20 Debtors - Group

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

Debtors - Charity

Amounts falling due within one year:	2024 £	2023 £
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
	288,959	256,749

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
	938,734	560,275

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
	249,725	94,935

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
Defined contribution schemes	£	£
Charge to profit or loss in respect of defined contribution schemes	51,082	59,156

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).

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
	202,145	464,777	(502,002)	164,920

Previous year:	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
	237,612	323,896	(359,363)	202,145
	237,612	323,896	(359,363)	202,145

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.

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
	2,143,805	1,469,958	(1,360,070)	-	2,253,693

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
	2,291,716	1,489,085	(1,636,996)	-	2,143,805
	2,291,716	1,489,085	(1,636,996)	-	2,143,805

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	-	-	-	-	-
	2,143,805	693,405	(583,517)	-	2,253,693

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	-	-	-	-	-
	2,291,716	925,085	(1,072,996)	-	2,143,805
	2,291,716	925,085	(1,072,996)	-	2,143,805

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
	2,253,693	164,920	2,418,613

25 Analysis of net assets between funds **(Continued)**

	Unrestricted funds 2023	Restricted funds 2023	Total 2023
	£	£	£
At 31 December 2023:			
Tangible assets	1,006,049	-	1,006,049
Investments	628,497	-	628,497
Current assets/(liabilities)	509,259	202,145	711,404
	2,143,805	202,145	2,345,950

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.

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

28 Analysis of changes in net funds

The charity had no material debt during the year.

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

England & Wales - Charity number 1143472

Accounts

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

xeinadin auditing

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	Group Chief Executive
	John Illankovan	Head of Group Finance
	Sophie Thomas	Senior Head of Patient Services and Clinical Liaisons
	Anna Featherstone	Head of Fundraising
	Steve Cotterell	Head of Support and Advocacy
	Toni Ellerton	Executive Assistant and Company Secretary
	Barbara Cotterell	HR Lead
	Helen Crawley	Head of Communications
	Tom Kenny	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

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SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CHAIRMAN'S STATEMENT

FOR THE YEAR ENDED 31 DECEMBER 2023

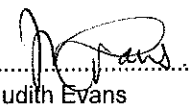
After all the excitement of our 40th Anniversary Year in 2022 we have used 2023 as a year to regroup and plan for the future. In doing so we released our strategic plan for the next three years which set the focus of our support on mental health and wellbeing. We continue to put our members at the centre 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, Geleo Physic Dysplasia, GM-1 Gangliosidosis, Lysosomal Acid Lipase Deficiency (LAL D), Alpha-Mannosidosis, Beta-Mannosidosis, MSD Multiple sulphatase deficiency, Metachromatic Leukodystrophy, ML I Neuramidase Deficiency, ML II i-cell disease, ML III Pseudo Hurler Polydystrophy, ML IV, Sialic Acid Storage Disease, Winchester, Gaucher and Farber disease.

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 bought 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.

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.

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.

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.

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.

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.

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.

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.

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.

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 FCCA (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

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
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		2,143,805	202,145	2,345,950	2,291,716	237,612	2,529,328

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

The financial statements were approved by the trustees on 02/06/24

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

The financial statements were approved by the trustees on 02/06/24

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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 £	2023 £	2022 £	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	
Net cash (used in)/generated from investing activities			(266,914)		25,426
Net cash used in financing activities			-		-
Net decrease in cash and cash equivalents			(556,489)		(413,527)
Cash and cash equivalents at beginning of year			1,287,900		1,701,427
Cash and cash equivalents at end of year			731,411		1,287,900

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.

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 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.

Allocation of support costs

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	Striaght 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.

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.

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
	201,290	190,139

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
	278,845	323,896	602,741	102,297	369,420	471,717

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	958,230	1,025,521

7 Income from investments

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

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
	158,534	149,255
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
	612,973	505,428
Total costs	771,507	654,683

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
	564,058	139,344	274,923	-	978,325
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
	714,652	184,522	274,923	50,755	1,224,852
Analysis by fund					
Unrestricted funds	355,289	184,522	274,923	50,755	865,489
Restricted funds	359,363	-	-	-	359,363
	714,652	184,522	274,923	50,755	1,224,852

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
	530,679	155,962	262,147	-	948,788
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
	675,362	199,367	262,147	219,368	1,356,244
Analysis by fund					
Unrestricted funds	368,152	199,367	262,147	219,368	1,049,034
Restricted funds	307,210	-	-	-	307,210
	675,362	199,367	262,147	219,368	1,356,244

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.

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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 expesnes	20,163	9,853
Governance costs	104,914	116,804
	376,851	253,020
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
	376,851	253,020

Governance costs comprise:	2023 £	2022 £
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
	104,914	116,804

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.

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.

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

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
At 31 December 2023	6,100	622,397	-	628,497
Carrying amount				
At 31 December 2023	6,100	622,397	-	628,497
At 31 December 2022	6,100	311,026	-	317,126

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
At 31 December 2023	6,100	622,397	2	628,499
Carrying amount				
At 31 December 2023	6,100	622,397	2	628,499
At 31 December 2022	6,100	311,026	2	317,128

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.

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

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

Debtors - Charity

Amounts falling due within one year:	2023 £	2022 £
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
	256,749	447,601

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
	560,275	478,508

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
	94,935	62,671

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).

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
	237,612	323,896	(359,363)	202,145

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
	175,402	369,420	(307,210)	237,612

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.

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 developement fund	166,684	-	(68,448)	98,236
Building refurbishment fund	100,000	-	-	100,000
Christine Lavery memorial fund	100,000	-	-	100,000
	2,291,716	1,489,085	(1,636,996)	2,143,805

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 developement fund	270,502	-	(103,818)	166,684
Building refurbishment fund	100,000	-	-	100,000
Christine Lavery memorial fund	100,000	-	-	100,000
	2,643,610	1,351,823	(1,703,717)	2,291,716

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.

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
	2,143,805	202,145	2,345,950

	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
	2,291,716	237,612	2,529,328

24 Related party transactions

Transactions with related parties

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	(289,573)	(438,953)

26 Analysis of changes in net funds

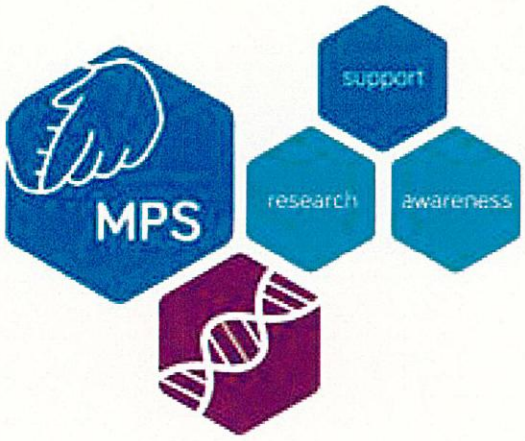
The charity had no material debt during the year.

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

England & Wales - Charity number 1143472

Accounts

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



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

xeinadin auditing

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for the Year Ended 31 December 2022

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REFERENCE AND ADMINISTRATION DETAILS
for the Year Ended 31 December 2022

Trustees & Directors

Katy Brown	
Sarah Burgess	
Judith Mary Evans	
James Henry Garthwaite	
Dr Gordon Robert Harvey	(resigned 30.04.22)
Prof Atul Bhanu Mehta	(resigned 30.04.22)
Prof Simon James Heales	(appointed 22.11.22)
Prof Derralynn Arlene Hughes	(appointed 26.11.22)
David Maurice Patton	
Phillip John Pearson	
Wilma Robins	
Dr Fiona Stewart	
Bryan Gordon Winchester	

Registered Company number
7726882 (England and Wales)

Registered Charity number
1143472 / SCO41012

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

Company Secretary
Toni Ellerton

Group Chief Executive Officer
Robert Stevens

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

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

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

CHAIRMAN'S STATEMENT
for the Year Ended 31 December 2022

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

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

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

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

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

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

Judith Evans, Chair of Trustees
24 June 2023

The trustees (who are also the directors of the charity for the purposes of the Companies Act) present their report together with the audited financial statements of the Society for Mucopolysaccharide Diseases (the charity and the group) for the year ended 31 December 2022.

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

OBJECTIVES AND ACTIVITIES

Principal activity

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

Objectives and aims

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

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

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

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

To do this, we rely on:

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

What are MPS and related lysosomal diseases?

Mucopolysaccharide (MPS), Fabry and related lysosomal diseases are a group of rare, genetic diseases that affect the functioning of particular enzymes in the body causing waste materials to accumulate and disrupt the functioning of the body's cells. People born with an MPS or related disease are unable to produce enzymes essential for the continual process of breaking down and replacing used materials. Babies may show no sign of the disease, but as more and more cells become damaged by the storage of used material, symptoms begin to appear. Sadly, these are progressive diseases which lead to an increase in problems as the years go by. Effects of the disease vary but are all associated with progressive physical disability. Over half these diseases cause degeneration of the brain resulting in severe learning difficulties and death in childhood.

We support people who have one of 27 diseases. The full list of conditions we support is: MPS I Hurler, MPS I Hurler Scheie, MPS I Scheie, MPS II Hunter, MPS III Sanfilippo, MPS IVA Morquio, MPS VI Maroteaux-Lamy, MPS VII Sly, MPS IX Natowicz, Fabry disease, Aspartylglycosaminuria (AGU), Fucosidosis, Geleo Physic Dysplasia, GM-1 Gangliosidosis, Lysosomal Acid Lipase Deficiency (LAL D), Alpha-Mannosidosis, Beta-Mannosidosis, MSD Multiple sulphatase deficiency, Metachromatic Leukodystrophy, ML I Neuramidase Deficiency, ML II i-cell disease, ML III Pseudo Hurler Polydystrophy, ML IV, Sialic Acid Storage Disease, Winchester, Gaucher and Farber disease.

PUBLIC BENEFITS AND ACHIEVEMENTS OF MPS SOCIETY'S WORK PERFORMED

Access to Exceptional Support and Advice

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

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

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

Support events
At the beginning of the year we ran online workshops for parents and carers on how to support siblings in partnership with Sibs, a charity for brothers and sisters of disabled children and adults. We also held some fun online sessions including painting, comedy bingo and quizzes as part of our 40th celebrations.
We were able to hold face-to-face support events for the first time in a while and this was welcomed by our community. The first trip to Legoland was oversubscribed and was followed by other theme park days later in the year.

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

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

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

Access to world-class clinical care

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

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

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

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

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

Access to effective treatments

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

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

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

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

Operating effective processes

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

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

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

Fundraising and donations

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

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

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

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

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

Trusts and pharmaceutical

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

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

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

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

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

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

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

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

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

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

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

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

GOVERNANCE

Governing document
The Society is controlled by its governing document, a deed of trust, and constitutes a company, limited by guarantee, as defined by the Companies Act 2006.

The Society was founded in 1982 and was registered with the Charity Commission in 1983 as an unincorporated association, registered charity number 287034. On 2 August 2011 the Society incorporated as a company limited by guarantee with the name 'Society for Mucopolysaccharide Diseases'. The assets, liabilities and activities of the Society were transferred into this charitable company on 1 November 2011.

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

Induction and training of new trustees
New trustees are provided with information about the Society and its work, the role and responsibilities of trustees, and the composition and workings of the Board. They are given copies of the Society's governing instrument, a folder of all the Society's policies and the minutes of the last five Board of trustees meetings. Trustees are regularly provided with the latest information on employment and charity law.

Pay policy for key management personnel
The Board of trustees are responsible for defining the Society's pay policy and setting the annual salary for the Chief Executive.

Organisational structure
The Society is governed by a Board of up to 13 trustees known as the Board of directors which meets a minimum of five times during the year. The day to day business of the Society is managed by the CEO and is governed by the Articles of Association.

Wider network
One trustee's first language is Welsh and others live in Scotland. Geographically, the MPS Society provides a UK wide support and individual advocacy service from MPS House based in Amersham in Buckinghamshire. Our employees are central to providing the support, individual advocacy services and the communication of our cause, while our supporters enable us to achieve our goals and objectives.

Risk management
The trustees have identified the level of risks to which the Society may be exposed and have established the implementation of a risk management strategy which comprises quarterly reviews of the risks the Society may face, systems and procedures to mitigate these risks and implementation of procedures designed to report on and minimise any potential impact on the Society should any of these risks materialise.

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

Risk Sub-Committee
In 2022 a Risk Sub-Committee was formally established, with clear terms of reference and guiding principles. Identifying best practice from the Charity Commission and using the expert knowledge of selected trustees, a new structure and process was created. Today, the society benefits from a formalised and structured risk management process using insights from the board and expert opinions from the senior staff leadership team. The risk matrix is refreshed on a monthly basis and shared and discussed at each board meeting. The new risk management matrix allows for the simple comprehension of live risks, the archive of old and enables reporting aligned to our strategic goals.

GOVERNANCE (CONTINUED)

Audit and Finance Sub-Committee

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

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

Clinical and Scientific Advisory Sub-Committee (CSAC)

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

The main function are:

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

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

FINANCIAL REVIEW

The MPS Society continues to raise and receive funds through applications to grant giving bodies to support its advocacy service and charitable events, including the salaries of the senior advocacy officer and four advocacy officers, as well as special projects. The Society continues to rely heavily throughout the year on its members and supporters' efforts to raise income by way of donations and fundraising. Income derived from charitable activities (being grants, events and awareness) totalled £471,717 in comparison to £334,518 in 2021. Receipts from donations £174,931 compared with £189,116 in 2021. This year legacies of £15,208 were received whereas £18,299 of legacies were received in 2021.

MPS Commercial Limited (trading as Rare Disease Research Partners) is a wholly owned trading subsidiary of the MPS Society. All logistical services related to Patient Access to Clinical Trials and work involving Health Technology Assessments and Patient Reported Outcomes are carried out by MPS Commercial. In 2022, MPS Commercial were able to donate £232,465 (2021: £133,218) to the MPS Society. RDRP retains operational independence from the charity with its own Board and CEO. Transactions are undertaken with third parties on a strictly commercial basis and kept wholly separate to dealings with the charity. Potential or actual conflicts arising are regularly reviewed and actively managed in line with the group's conflict of interest policy.

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

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

RESERVES POLICY

In the year, ending 31 December 2022 the trustees reviewed the charity's reserves policy to ensure that it is flexible enough to withstand the high and lows of funding, and be robust in its ability to secure the future of our services. In so doing, the trustees agreed to the established policy whereby the unrestricted funds not committed or invested in tangible fixed assets ('the free reserves') held by the charity should be six months of the unrestricted resources. In accordance with good practice, this is reviewed each year to ensure that it fairly reflects the needs of the society. The review in the current year concluded that the current policy of aiming for reserves of six months of the unrestricted resources remains appropriate. Current year our six months core expenditure equates to £667,547 (2021: £790,626). The level of free reserves as at 31 December 2022 amounted to £742,845 (2021: £745,346) which amounts to 6 months of overall expenditure of the society.

LOOKING FORWARD

Our focus in 2023 is to deliver services to support the mental health and wellbeing of individuals and families and continue providing the resources that have already proved useful. We will analyse the results of our latest survey on supporting siblings to tailor our support to fit their needs. We will be reviewing our bereavement service and resources and will continue our work and support to young people through our 'Rare Voices' group.

STATEMENT OF TRUSTEES RESPONSIBILITIES

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

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

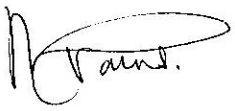
- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity Statement of Recommended Practice (SORP);
- make judgements and estimates that are reasonable and prudent;
  state whether applicable UK Accounting Standards have been followed,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

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

Disclosure of information to auditors

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

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



Judith Evans, Chair of Trustees
24 June 2023

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

Opinion

We have audited the financial statements of The Society For Mucopolysaccharide Diseases (the 'charitable parent company') and its subsidiaries ('the group') for the year ended 31 December 2022 which comprise the group statement of financial activities, the group balance sheet, the charitable company balance sheet, the group statement of cash flows and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

In our opinion the financial statements:

- give a true and fair view of the state of the group's and the charitable company's affairs as at 31 December 2022 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of the other information, we are required to report that fact.

We have nothing to report in this regard.

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

Opinion on other matters prescribed by the Companies Act 2006
In our opinion, based on the work undertaken in the course of the audit:

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

Matters on which we are required to report by exception
In the light of the knowledge and understanding of the environment of the charitable company and the group obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Report of the Trustees.

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

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

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

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

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

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

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

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

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

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

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

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

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

Chartered Accountants
Statutory Auditor

3.7.23

2 Hilliards Court
Chester Business Park
Chester
Cheshire
CH4 9PX

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) for the Year Ended 31 December 2022

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

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

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL POSITION
At 31 December 2022

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

As permitted by s408 Companies Act 2006, the charitable company has not presented its own statement of financial activities and related notes. The charitable company's deficit for the year was £289,684 (2021: surplus £138,005).

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

.....

Judith Evans, Chair of Trustees

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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

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

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

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

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

2 ANALYSIS OF CHANGES IN NET FUNDS

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

1. ACCOUNTING POLICIES

Charity information
The Society For Mucopolysaccharide Diseases is a registered charity and private company limited by guarantee incorporated in England and Wales. The registered office is MPS House, Repton Place, White Lion Road, Amersham, Buckinghamshire, HP7 9LP.

The group consists of The Society For Mucopolysaccharide Diseases and all of its subsidiaries.

The Charitable Company's financial statements have been prepared in compliance with the Charities SORP FRS 102 issued 1 January 2015 (update bulletin 2, effective 1 January 2019).

1.1 Accounting convention

The Group and Charity financial statements have been prepared in accordance with the Statement of Recommended Practice: "Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (SORP) issued on 16 July 2014 and the "Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland" (FRS 102). They also comply with the reporting requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 and the Charities Act 2011. The charitable company is a Public Benefit Entity as defined by FRS 102. The financial statements are prepared in sterling, which is the functional currency of the group. Monetary amounts in these financial statements are rounded to the nearest £.

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

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

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

1.2 Basis of consolidation

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

All financial statements of subsidiaries are made up to 31 December 2022.

All intra-group transactions, balances and unrealised gains on transactions between group companies are eliminated on consolidation. Unrealised losses are also eliminated unless the transaction provides evidence of an impairment of the asset transferred.

1. ACCOUNTING POLICIES (CONTINUED)

1.3 Preparation of the accounts on a going concern basis

The trustees have considered the future trading of the charitable company and the group and have prepared cash flow forecasts for a period of 12 months from the date of these financial statements.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charitable company and group has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.4 Incoming resources

Income is stated after trade discounts and other sales taxes.

Voluntary income

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

Grants receivable

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

Legacies

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

Donations in kind

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

Investment income

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

Income from other trading activities

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

1.5 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources. Grants payable are included in the statement of financial activities in the year in which they relate. Grants offered subject to conditions which have not been met at the yearend date are noted as a commitment but not accrued as expenditure.

1.6 Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include Head Office costs, finance, personnel, payroll and governance costs. Governance costs are those incurred in connection with administration of the charity and compliance with constitutional and statutory requirements. These are apportioned based on staff numbers.

1. ACCOUNTING POLICIES (CONTINUED)

1.7 Pass-through costs and reimbursements

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

1.8 Fund accounting

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

1.9 Tangible fixed assets

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

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

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

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

1.10 Fixed asset investments

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

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

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

1.11 Debtors

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

1.12 Cash at bank and in hand

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

1.13 Creditors and provisions

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

1.14 Taxation

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

1. ACCOUNTING POLICIES (CONTINUED)

1.15 Pension costs and other post-retirement benefits

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

1.16 Financial Instruments

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

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

Basic financial assets

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

Basic financial liabilities

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

Derecognition of financial liabilities

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

2. LEGAL STATUS

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

3. DONATIONS AND LEGACIES

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

4. INCOME FROM CHARITABLE ACTIVITIES

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

INCOME FROM CHARITABLE ACTIVITIES – 2021 COMPARATIVES

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

5. OTHER TRADING ACTIVITIES

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

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

6. INVESTMENT INCOME

	2022 £	2021 £
Rent receivable	29,951	25,424
Interest receivable	3,271	4,570
	33,222	29,994

All investment income is recorded in the unrestricted fund.

7. EXPENDITURE ON RAISING FUNDS

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

EXPENDITURE ON RAISING FUNDS – 2021 COMPARATIVES

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

8. EXPENDITURE ON CHARITABLE ACTIVITIES

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

EXPENDITURE ON CHARITABLE ACTIVITIES – 2021 COMPARATIVES

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

9. OTHER EXPENDITURE

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

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

10. ALLOCATION OF DIRECT COSTS

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

11. ALLOCATION OF SUPPORT COSTS

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

12. GRANTS PAYABLE

	2022	2021
	£	£
Grants and donations	219,368	-

Grants payable to institutions

	2022	2021
	£	£
Research grants	214,455	-

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

13. NET INCOME/(EXPENDITURE)

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

	2022	2021
	£	£
Auditors' remuneration	6,000	6,000
Auditors' remuneration – non audit services	1,200	1,200
Depreciation	34,141	33,584

14. TRUSTEES' REMUNERATION AND BENEFITS

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

All trustees are reimbursed for their expenses or expenses are paid for by the charity on behalf of trustees, which are necessarily incurred in attending management committee meetings and in performing their duties as trustees. The Chief Executive Officer of the Society approves the reimbursement of such expenses. In 2022 these totalled £1,043 (2021: £1,560) for all trustees.

15. STAFF COSTS

	Group		Charity	
	2022	2021	2022	2021
	£	£	£	£
Wages and salaries	1,113,275	1,051,363	546,730	493,156
Social security costs	117,651	101,771	56,134	44,105
Other pension costs	52,195	47,356	24,890	22,713
	1,283,121	1,200,490	627,754	559,974

The allocation of pension costs between funds follows the allocation of the associated employee remuneration.

The average monthly number of employees during the year was as follows:

	Group		Charity	
	2022	2021	2022	2021
	£	£	£	£
Chief executives	2	2	1	1
Administration	5	4	5	4
Advice, information & support	14	12	14	12
Commercial trading operation	13	15	-	-
	34	33	20	17

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

	Group		Charity	
	2022	2021	2022	2021
	£	£	£	£
In the band £90,001 - £100,000	1	1	1	1
In the band £120,001 - £130,000	-	1	-	-
In the band £130,001 - £140,000	1	-	-	-
	2	2	1	1

The key management personnel of the group, comprise the trustees, the group chief executive officer, the commercial chief executive officer, head of advocacy, head of fundraising and head of finance. The total employee benefits of the key management personnel were £359,893 (2021: £399,366). The highest paid employee of the charity had accrued £5,048 (2021: £4,760) in employer pension contributions and the highest paid employee of the group had accrued £6,555 (2021: £6,439) in employer pension contributions.

16. 2021 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Note	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME					
Voluntary income:					
Donations & legacies	3	207,415	-	207,415	296,209
Activities for generating funds:					
Charitable activities	4	52,163	282,355	334,518	710,104
Other trading activities	5	871,319	-	871,319	1,023,060
Investment income	6	29,994	-	29,994	26,073
TOTAL INCOME		1,160,891	282,355	1,443,246	2,055,446
EXPENDITURE					
Raising funds:	7				
Fundraising grants & donations		71,148	-	71,148	63,563
Fundraising activities		69,045	-	69,045	74,782
Trading activities		457,695	-	457,695	542,882
		597,888	-	597,888	681,227
Charitable activities:	8				
Advocacy services & member events		45,533	425,003	470,536	488,171
Awareness raising		160,353	-	160,353	124,486
Trading activities		256,206	-	256,206	167,301
		462,092	425,003	887,095	779,958
Other costs		96,268	-	96,268	95,694
TOTAL EXPENDITURE		1,156,248	425,003	1,581,251	1,513,142
NET INCOME / (EXPENDITURE)		4,643	(142,648)	(138,005)	542,304
RECONCILIATION OF FUNDS					
Total funds brought forward		2,638,967	318,050	2,957,017	2,414,713
TOTAL FUNDS CARRIED FORWARD		**2,643,610**	**175,402**	**2,819,012**	**2,957,017**

17. TANGIBLE FIXED ASSETS

Group	Freehold Land and buildings	Plant and Equipment	Totals
COST	£	£	£
At 1 January 2022	1,435,389	63,476	1,498,865
Additions	-	6,662	6,662
Disposals	-	-	-
At 31 December 2022	1,435,389	70,138	1,505,527
DEPRECIATION			
At 1 January 2022	379,577	57,551	437,128
Charge for year	28,708	5,433	34,141
Eliminated on disposal	-	-	-
At 31 December 2022	408,285	62,984	471,269
NET BOOK VALUE			
At 31 December 2022	1,027,104	7,154	1,034,258
At 31 December 2021	1,055,812	5,925	1,061,737

Charity	Freehold Land and buildings	Plant and Equipment	Totals
	£	£	£
COST			
At 1 January 2022	1,435,389	52,862	1,488,251
Additions	-	6,662	6,662
Disposals	-	-	-
At 31 December 2022	1,435,389	59,524	1,494,913
DEPRECIATION			
At 1 January 2022	379,577	48,209	427,786
Charge for year	28,708	4,797	33,505
Eliminated on disposal	-	-	-
At 31 December 2022	408,285	53,006	461,291
NET BOOK VALUE			
At 31 December 2022	1,027,104	6,518	1,033,622
At 31 December 2021	1,055,812	4,653	1,060,465

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

18. FIXED ASSET INVESTMENTS

	2022 Group £	2022 Charity £	2021 Group £	2021 Charity £
Shares in subsidiary	-	2	-	2
Donated jewellery	6,100	6,100	6,100	6,100
Investments in bank bonds	311,026	311,026	309,248	309,248
	317,126	317,128	315,348	315,350

Investment in subsidiaries

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

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

	MPS Commercial Limited		Rare Disease Research Partners Limited	
	2022 £	2021 £	2022 £	2021 £
Fixed assets	636	1,272	-	-
Current assets	847,669	942,831	1	1
Current liabilities	(848,304)	(944,102)	-	-
Aggregate share capital and reserves	1	1	1	1
Net income from trading activities	232,465	133,218	-	-

There were no investment assets outside the UK.

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

Investment in bank bonds
The Society for Mucopolysaccharide Diseases reinvested £311,027 in fixed business bonds, which are due to mature within less than one year. Of the £311,027 invested, £200,000 has been allocated to the designated fund - £150,000 for the Research Fund and £50,000 for the Service Development Fund.

19. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

20. CASH AT BANK AND IN HAND

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

21. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

Included within other creditors is deferred income of £187,140 (2021: £197,730). Deferred income is recognised in MPS Commercial where administration fees for patients are spread accordingly with their associated period. Deferred income in The Society For Mucopolysaccharide Diseases is recognised in respect of grants where the performance agreement runs across multiple periods. All of the deferred income recorded in 2022 has been subsequently recognised as income in 2021.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	2022 Unrestricted funds £	2022 Restricted funds £	2022 Total Funds £	2021 Unrestricted funds £	2021 Restricted Funds £	202 Total Funds £
Fixed assets	1,034,258	-	1,034,258	1,061,737	-	1,061,737
Investments	317,126	-	317,126	315,348	-	315,348
Current assets	1,418,839	237,613	1,656,452	1,841,122	175,402	2,016,524
Current liabilities	(478,508)	-	(478,508)	(574,597)	-	(574,597)
	2,291,715	237,613	2,529,328	2,643,610	175,402	2,819,012

23. STATEMENT OF FUNDS

Group

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

Charity

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

23. STATEMENT OF FUNDS (CONTINUED) 2021 COMPARITIVES

Group

	Funds at 1 January 2021	Income	Expenditure	Fund Transfers	Funds at 31 December 2021
Unrestricted funds					
General charitable	750,000	1,160,891	(1,127,539)	(33,352)	752,815
Property fund	1,084,520	-	(28,709)	-	1,055,811
Research fund	367,297	-	-	-	367,297
Service development	237,150	-	-	33,352	270,502
Building refurbishment	100,000	-	-	-	100,000
Christine Lavery	100,000	-	-	-	100,000
	804,447	-	-	33,352	837,799
Total unrestricted	2,638,967	1,160,891	(1,156,248)	-	2,366,043
Restricted funds					
MPS restricted	192,757	282,355	(425,003)	-	31,921
LSD restricted	15,916	-	-	-	16,749
Research restricted	109,377	-	-	-	109,377
Total restricted funds	318,050	282,355	(425,003)	-	175,402
Total Funds	2,957,017	**1,443,246**	**(1,581,251)**	**-**	**2,819,012**

Charity

	Funds at 1 January 2021	Income	Expenditure	Fund Transfers	Funds at 31 December 2021
Unrestricted funds					
General charitable	750,000	446,990	(413,638)	(33,352)	750,000
Property fund	1,084,520	-	(28,709)	-	1,055,811
Research fund	367,297	-	-	-	367,297
Service development	237,150	-	-	33,352	270,502
Building refurbishment	100,000	-	-	-	100,000
Christine Lavery	100,000	-	-	-	100,000
	804,446	-	-	-	837,769
Total unrestricted	2,638,967	446,990	(442,347)	-	2,643,610
Restricted funds					
MPS restricted	192,757	282,355	(425,003)	-	50,109
LSD restricted	15,916	-	-	-	15,916
Research restricted	109,377	-	-	-	109,377
Total restricted	318,050	282,355	(425,003)	-	175,402
Total Funds	**2,957,017**	**729,345**	**(867,350)**	**-**	**2,819,012**

23. STATEMENT OF FUNDS (CONTINUED)

Restricted funds
MPS restricted fund – to support Disease booklets and Advocacy services.
LSD restricted fund – to support Lysosomal Storage Disease related meetings and conferences.
Research restricted fund – to support MPS research related projects.

Designated funds
Research fund – to support MPS research related projects.
Service development fund – to develop MPS new service for members.
Building refurbishment fund – for the maintenance of MPS House.
Christine Lavery memorial fund – to support Christine Lavery's memorial charitable events.

24. RELATED PARTY DISCLOSURES

MPS Commercial Limited and Rare Disease Research Partners Limited are 100% owned subsidiaries of The Society for Mucopolysaccharide Diseases.

Included in other debtors within the charitable company is the intercompany balance of £432,465 (2021: £333,217). All the profits of MPS Commercial Limited for the period have been distributed by Gift Aid to the charity, these totalled £232,465 (2021: £133,218).

Rent and recharges of £20,000 (2022: £20,000) were made by The Society for Mucopolysaccharide Diseases to MPS Commercial Limited.

The Society for Mucopolysaccharide Diseases has provided MPS Commercial Limited with a £200,000 long-term loan (2021: £200,000) on which interest of £6,125 (2021: £4,200) was charged.

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

25. ULTIMATE CONTROLLING PARTY

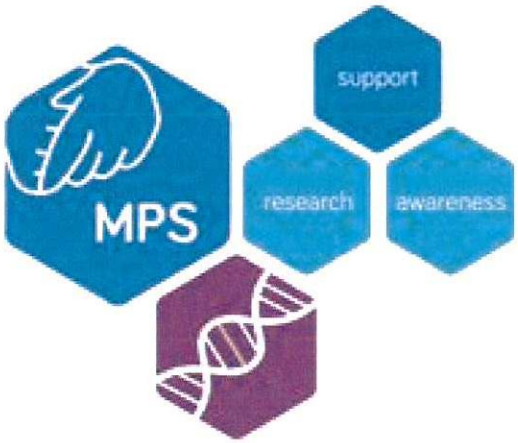
The board of trustees controls the charity.

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

England & Wales - Charity number 1143472

Accounts

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



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

xeinadin auditing

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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for the Year Ended 31 December 2021

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SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

REFERENCE AND ADMINISTRATION DETAILS
for the Year Ended 31 December 2021

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

Registered Company number
7726882 (England and Wales)

Registered Charity number
1143472 / SCO41012

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

Company Secretary
Toni Ellerton

Group Chief Executive Officer
Robert Stevens

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

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

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

CHAIRMAN'S STATEMENT
for the Year Ended 31 December 2021

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

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

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

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

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

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

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

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

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

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

James Garthwaite, Chair of Trustees

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

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

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

OBJECTIVES AND ACTIVITIES

Principal activity

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

Objectives and aims

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

In order to carry out these objectives:

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

To achieve these objectives, we rely on:

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

What are MPS and related lysosomal diseases?

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

Children born with an MPS or related disease are unable to produce enzymes essential for the continual process of breaking down and replacing used materials. Babies may show no sign of the disease, but as more and more cells become damaged by the storage of used material, symptoms begin to appear. Sadly, these are progressive diseases which lead to an increase in problems as the years go by. Effects of the disease vary but are all associated with progressive physical disability. Over half these diseases cause degeneration of the brain resulting in severe learning difficulties and death in childhood.

PUBLIC BENEFITS AND ACHIEVEMNTS OF MPS SOCIETY'S WORK PERFORMED

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

Covid-19 response

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

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

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

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

Support and advocacy service

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

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

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

Mental health and wellbeing

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

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

Sibling support

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

Virtual events

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

Take an active role in research

Research grants

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

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

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

Families receive the fastest possible diagnosis

Making recommendations on new initiatives

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

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

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

Champion new and existing treatments and therapies

Collaborating with patient services

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

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

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

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

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

Making it happen by investing in our future

Individual donations

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

Do your own thing

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

Events and challenges

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

Christmas Campaign

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

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

MPS Awareness Week

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

Trusts and pharmaceutical

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

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

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

Public Benefit compliance

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

Fundraising

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

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

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

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

GOVERNANCE

Governing document
The Society is controlled by its governing document, a deed of trust, and constitutes a company, limited by guarantee, as defined by the Companies Act 2006.

The Society was founded in 1982 and was registered with the Charity Commission in 1983 as an unincorporated association, registered charity number 287034. On 2 August 2011 the Society incorporated as a company limited by guarantee with the name 'Society for Mucopolysaccharide Diseases'. The assets, liabilities and activities of the Society were transferred into this charitable company on 1 November 2011.

Recruitment and appointment of new trustees
New trustees are elected by the membership and typically hold office for six years.

Induction and training of new trustees
New trustees are provided with information about the Society and its work, the role and responsibilities of trustees, and the composition and workings of the Board. They are given copies of the Society's governing instrument, a folder of all the Society's policies and the minutes of the last five Board of trustees meetings. Trustees are regularly provided with the latest information on employment and charity law.

Pay policy for key management personnel
The Board of trustees are responsible for defining the Society's pay policy and setting the annual salary for the Chief Executive.

Organisational structure
The Society is governed by a Board of up to 13 trustees known as the Board of directors which meets a minimum of five times during the year. The day to day business of the Society is managed by the CEO and is governed by the Articles of Association.

Wider network
One trustee's first language is Welsh and others live in Scotland. Geographically, the MPS Society provides a UK wide support and individual advocacy service from MPS House based in Amersham in Buckinghamshire. Our employees are central to providing the support, individual advocacy services and the communication of our cause, while our supporters enable us to achieve our goals and objectives.

Risk management
The trustees have identified the level of risks to which the Society may be exposed and have established the implementation of a risk management strategy which comprises quarterly reviews of the risks the Society may face, systems and procedures to mitigate these risks and implementation of procedures designed to report on and minimise any potential impact on the Society should any of these risks materialise.

GOVERNANCE (CONTINUED)

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

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

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

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

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

FINANCIAL REVIEW

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

MPS Commercial Limited (trading as Rare Disease Research Partners) is a wholly owned trading subsidiary of the MPS Society. All logistical services related to Patient Access to Clinical Trials and work involving Health Technology Assessments and Patient Reported Outcomes are carried out by MPS Commercial. In 2021, MPS Commercial were able to donate £133,218 (2020: £350,042) to the MPS Society. RDRP retains operational independence from the charity with its own Board and CEO. Transactions are undertaken with third parties on a strictly commercial basis and kept wholly separate to dealings with the charity. Potential or actual conflicts arising are regularly reviewed and actively managed in line with the group's conflict of interest policy.

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

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

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

RESERVES POLICY

In the year, ending 31 December 2021 the trustees reviewed the charity's reserves policy to ensure that it is flexible enough to withstand the high and lows of funding, and be robust in its ability to secure the future of our services. In so doing, the trustees agreed to the established policy whereby the unrestricted funds not committed or invested in tangible fixed assets ('the free reserves') held by the charity should be six months of the unrestricted resources. In accordance with good practice, this is reviewed each year to ensure that it fairly reflects the needs of the society. The review in the current year concluded that the current policy of aiming for reserves of six months of the unrestricted resources remains appropriate. Current year our six months overall expenditure equates to £790,626 (2020: £756,571). The level of free reserves as at 31 December 2021 amounted to £745,346 (2020: £745,480) which amounts to 5.7 months of overall expenditure of the society.

LOOKING FORWARD

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

STATEMENT OF TRUSTEES RESPONSIBILITIES

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

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

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity Statement of Recommended Practice (SORP);
- make judgements and estimates that are reasonable and prudent;

state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and

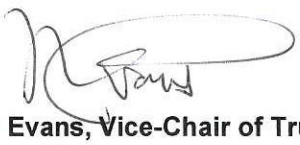
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

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

Disclosure of information to auditors

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

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



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

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

Opinion

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

In our opinion the financial statements:

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

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of the other information, we are required to report that fact.

We have nothing to report in this regard.

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

Opinion on other matters prescribed by the Companies Act 2006
In our opinion, based on the work undertaken in the course of the audit:

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

Matters on which we are required to report by exception
In the light of the knowledge and understanding of the environment of the charitable company and the group obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Report of the Trustees.

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

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

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

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

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

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

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

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

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

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

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

Use of our report

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

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

25th June 2022

Chartered Accountants
Statutory Auditor

2 Hilliards Court
Chester Business Park
Chester
Cheshire
CH4 9PX

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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

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

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

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL POSITION
At 31 December 2021

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

As permitted by s408 Companies Act 2006, the charitable company has not presented its own statement of financial activities and related notes. The charitable company's deficit for the year was £138,005 (2020: surplus £542,304).

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

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Judith Evans, Vice-Chair of Trustees

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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

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

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

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

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

2 ANALYSIS OF CHANGES IN NET FUNDS

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

1. ACCOUNTING POLICIES

Charity information

The Society For Mucopolysaccharide Diseases is a registered charity and private company limited by guarantee incorporated in England and Wales. The registered office is MPS House, Repton Place, White Lion Road, Amersham, Buckinghamshire, HP7 9LP.

The group consists of The Society For Mucopolysaccharide Diseases and all of its subsidiaries.

The Charitable Company's financial statements have been prepared in compliance with the Charities SORP FRS 102 issued 1 January 2015 (update bulletin 2, effective 1 January 2019).

1.1 Accounting convention

The Group and Charity financial statements have been prepared in accordance with the Statement of Recommended Practice: "Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (SORP) issued on 16 July 2014 and the "Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland" (FRS 102). They also comply with the reporting requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 and the Charities Act 2011. The charitable company is a Public Benefit Entity as defined by FRS 102. The financial statements are prepared in sterling, which is the functional currency of the group. Monetary amounts in these financial statements are rounded to the nearest £.

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

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

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

1.2 Basis of consolidation

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

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

All intra-group transactions, balances and unrealised gains on transactions between group companies are eliminated on consolidation. Unrealised losses are also eliminated unless the transaction provides evidence of an impairment of the asset transferred.

1. ACCOUNTING POLICIES (CONTINUED)

1.3 Preparation of the accounts on a going concern basis

The trustees have considered the future trading of the charitable company and the group and have prepared cash flow forecasts for a period of 12 months from the date of these financial statements.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charitable company and group has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.4 Incoming resources

Income is stated after trade discounts and other sales taxes.

Voluntary income

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

Grants receivable

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

Legacies

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

Donations in kind

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

Investment income

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

Income from other trading activities

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

1.5 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources. Grants payable are included in the statement of financial activities in the year in which they relate. Grants offered subject to conditions which have not been met at the yearend date are noted as a commitment but not accrued as expenditure.

1.6 Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include Head Office costs, finance, personnel, payroll and governance costs. Governance costs are those incurred in connection with administration of the charity and compliance with constitutional and statutory requirements. These are apportioned based on staff numbers.

1. ACCOUNTING POLICIES (CONTINUED)

1.7 Pass-through costs and reimbursements

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

1.8 Fund accounting

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

1.9 Tangible fixed assets

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

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

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

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

1.10 Fixed asset investments

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

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

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

1.11 Debtors

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

1.12 Cash at bank and in hand

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

1.13 Creditors and provisions

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

1.14 Taxation

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

1. ACCOUNTING POLICIES (CONTINUED)

1.15 Pension costs and other post-retirement benefits

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

1.16 Financial Instruments

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

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

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

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

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

2. LEGAL STATUS

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

3. DONATIONS AND LEGACIES

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

4. INCOME FROM CHARITABLE ACTIVITIES

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

INCOME FROM CHARITABLE ACTIVITIES – 2020 COMPARATIVES

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

5. OTHER TRADING ACTIVITIES

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

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

6. INVESTMENT INCOME

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

All investment income is recorded in the unrestricted fund.

7. EXPENDITURE ON RAISING FUNDS

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

EXPENDITURE ON RAISING FUNDS – 2020 COMPARATIVES

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

8. EXPENDITURE ON CHARITABLE ACTIVITIES

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

EXPENDITURE ON CHARITABLE ACTIVITIES – 2020 COMPARATIVES

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

9. OTHER EXPENDITURE

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

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

10. ALLOCATION OF DIRECT COSTS

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

11. ALLOCATION OF SUPPORT COSTS

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

12. GRANTS PAYABLE

	2021	2020
	£	£
Grants and donations	-	9,400

Grants payable to institutions

	2021	2020
	£	£
Salford Royal NHS Foundation Trust	-	9,400

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

13. NET INCOME/(EXPENDITURE)

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

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

14. TRUSTEES' REMUNERATION AND BENEFITS

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

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

15. STAFF COSTS

	Group		Charity	
	2021	2020	2021	2020
	£	£	£	£
Wages and salaries	1,051,363	924,436	493,156	439,017
Social security costs	101,771	88,881	44,105	38,114
Other pension costs	47,356	42,677	22,713	21,193
	1,200,490	1,055,994	559,974	498,324

The allocation of pension costs between funds follows the allocation of the associated employee remuneration.

The average monthly number of employees during the year was as follows:

	Group		Charity	
	2021	2020	2021	2020
	£	£	£	£
Chief executives	2	2	1	1
Administration	4	3	4	3
Advice, information & support	12	14	12	14
Commercial trading operation	15	11	-	-
	33	30	17	18

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

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

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

16. 2020 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

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

17. TANGIBLE FIXED ASSETS

Group	Freehold Land and buildings	Plant and Equipment	Totals
	£	£	£
COST			
At 1 January 2021	1,435,389	57,767	1,493,156
Additions	-	5,709	5,709
Disposals	-	-	-
At 31 December 2021	1,435,389	63,476	1,498,865
DEPRECIATION			
At 1 January 2021	350,869	52,675	403,544
Charge for year	28,708	4,876	33,584
Eliminated on disposal	-	-	-
At 31 December 2021	379,577	57,551	437,128
NET BOOK VALUE			
At 31 December 2021	1,055,812	5,925	1,061,737
At 31 December 2020	1,084,520	5,092	1,089,612

Charity	Freehold Land and buildings	Plant and Equipment	Totals
	£	£	£
COST			
At 1 January 2021	1,435,389	49,061	1,484,450
Additions	-	3,801	3,801
Disposals	-	-	-
At 31 December 2021	1,435,389	52,862	1,488,251
DEPRECIATION			
At 1 January 2021	350,869	44,541	395,410
Charge for year	28,708	3,668	32,376
Eliminated on disposal	-	-	-
At 31 December 2021	379,577	48,209	427,786
NET BOOK VALUE			
At 31 December 2021	1,055,812	4,653	1,060,465
At 31 December 2020	1,084,520	4,520	1,089,040

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

18. FIXED ASSET INVESTMENTS

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

Investment in subsidiaries

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

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

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

There were no investment assets outside the UK.

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

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

19. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

20. CASH AT BANK AND IN HAND

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

21. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

Included within other creditors is deferred income of £197,730 (2020: £209,953). Deferred income is recognised in MPS Commercial where administration fees for patients are spread accordingly with their associated period. Deferred income in The Society For Mucopolysaccharide Diseases is recognised in respect of grants where the performance agreement runs across multiple periods. All of the deferred income recorded in 2021 has been subsequently recognised as income in 2022.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

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

23. STATEMENT OF FUNDS

Group

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

Charity

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

23. STATEMENT OF FUNDS (CONTINUED) 2020 COMPARITIVES

Group

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

Charity

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

23. STATEMENT OF FUNDS (CONTINUED)

Restricted funds

MPS restricted fund – to support Disease booklets and Advocacy services.
LSD restricted fund – to support Lysosomal Storage Disease related meetings and conferences.
Research restricted fund – to support MPS research related projects.

Designated funds

Research fund – to support MPS research related projects.
Service development fund – to develop MPS new service for members.
Building refurbishment fund – for the maintenance of MPS House.
Christine Lavery memorial fund – to support Christine Lavery's memorial charitable events.

24. RELATED PARTY DISCLOSURES

MPS Commercial Limited and Rare Disease Research Partners Limited are 100% owned subsidiaries of The Society for Mucopolysaccharide Diseases.

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

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

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

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

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

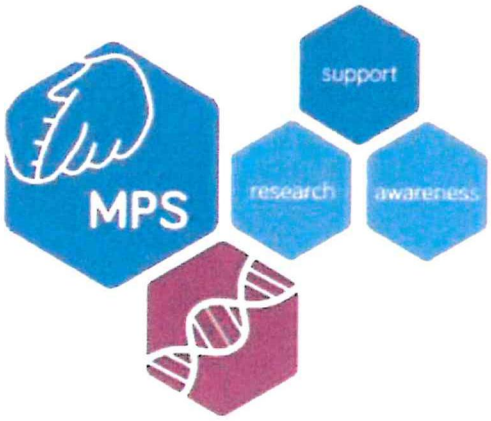
25. ULTIMATE CONTROLLING PARTY

The board of trustees controls the charity.

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

England & Wales - Charity number 1143472

Accounts



SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES
REPORT OF THE TRUSTEES AND AUDITED CONSOLIDATED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

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

McLINTOCKS
CHARTERED ACCOUNTANTS AND BUSINESS ADVISORS
A Xeinadin Company

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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for the Year Ended 31 December 2020

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SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

REFERENCE AND ADMINISTRATION DETAILS
for the Year Ended 31 December 2020

Trustees & Directors

Katy Joanne Brown	Appointed 28 November 2020
Sarah Burgess	
Judith Mary Evans	
James Henry Garthwaite	
Dr Gordon Robert Harvey	
Prof Atul Bhanu Mehta	
David Maurice Patton	
Phillip John Pearson	
Wilma Robins	
Dr Fiona Jane Stewart	Appointed 4 April 2020
Bryan Gordon Winchester	

Registered Company number
7726882 (England and Wales)

Registered Charity number
1143472 / SCO41012

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

Company Secretary
Robert Stevens

Group Chief Executive Officer
Robert Stevens

Auditors
McLintocks (NW) Limited, 2 Hilliards Court, Chester Business Park, Chester, CH4 9PX

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

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CHAIRMAN'S STATEMENT
for the Year Ended 31 December 2020

2020 has been a year like no other. The threat of COVID-19 had profound impacts on our members, many of whom are in the 'highly vulnerable' category. Many individuals and families had to shield for months, having to manage the mental and physical challenges of lockdown. At the same time, they had to cope with complex medical conditions, often without the vital face-to-face support that they depend upon. Many hospital appointments and operations were cancelled, home infusions became very complex to arrange, and other support services were reduced. As a result of these challenges, our members needed our support more than ever, and continue to do so in 2021.

The Society rose to the challenge by delivering a real step-change in service. This was possible thanks to the remarkable efforts of the staff team. None were furloughed and, with the Society's offices shut from mid-March, many worked extra hours to support members. They did this without the support and camaraderie that has always been so precious in the office and while coping with the impact of COVID on their own families. I speak on behalf of all of our members in giving heartfelt thanks to 'team MPS' for all that they did in the year.

Through the pandemic more than 1,000 members and their families were contacted and offered additional support. All face-to-face and clinic visits were also made virtually by members of our Advocacy and Support team. This team continues to provide invaluable support, by phone and video-conference, from 7am to 10pm seven days a week.

To help families desperate to understand the implications of COVID and lockdown, we offered a programme of webinars providing the latest information, answering questions and building connections. In total, we delivered 16 webinars which were very well received, with the most popular attracting more than 1,100 views on our website. The website also provided up-to-date and specific guidance about COVID-19 for those with an inherited metabolic disease and signposted families to the most relevant NHS and government advice.

A sense of community is vital in difficult times and, despite our entire 2020 events programme being postponed, we were determined to bring our members closer together. We ran a series of online 'Events for All', from quizzes to scavenger hunts, cooking lessons and a Christmas Panto, all helping to reduce feelings of isolation. We also launched a 'Treats for All' programme, offering vouchers to members providing them with some much needed light-hearted relief. Regular social media posts helped to ensure that families felt part of an increasingly supportive and vibrant society. Since the start of the pandemic, we have had a huge increase in visits to the website relative to the previous years.

We are enormously grateful to our donors who helped ensure that we had the funding necessary to get through this difficult year. Overall, the charity made a significant surplus helped by a contribution of £350,000 from MPS Commercial trading as Rare Disease Research Partners ('RDRP'). RDRP is a business that provides services to the rare disease community and is wholly owned by the MPS Society. The majority of this surplus has been designated by the Board of Trustees to address two rapidly emerging needs in 2021 - mental health and community resilience.

During the year we also made further funds available for research projects. The Board awarded grants for two projects: the first for research into the use of a digital microfluidics platform for the rapid assessment of lysosomal enzyme activity; the second to research how hydrotherapy can help alleviate pain and improve mobility in patients with MPS conditions. We look forward to many more research grant applications in the coming year.

Looking ahead we know that the pandemic will pass but, with funding diverted to COVID-related programmes, ultra-rare diseases face a particularly challenging climate in the UK.

CHAIRMAN'S STATEMENT
for the Year Ended 31 December 2020

Despite the inevitable consequences on Government policy and budgets, we are working to ensure that all our community have access to:

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

In the coming years, the role of the Society, working with the broader Lysosomal Storage Disease (LSD) community in the UK and worldwide, will be more important than ever. We can take encouragement from knowing that, against all the odds, the MPS Society finished 2020 better connected and better resourced to take on that challenge.

James Garthwaite, Chair of Trustees

TRUSTEES REPORT (INCLUDING DIRECTOR'S REPORT)
for the Year Ended 31 December 2020

The trustees (who are also the directors of the charity for the purposes of the Companies Act) present their report together with the audited financial statements of the Society for Mucopolysaccharide Diseases (the charity and the group) for the year ended 31 December 2020.

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

OBJECTIVES AND ACTIVITIES

Principal activity

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

Objectives and aims

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

In order to carry out these objectives:

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

To achieve these objectives, we rely on:

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

What are MPS and related lysosomal diseases?
MPS and related diseases are rare diseases affecting one baby born every 8 days in the United Kingdom.

MPS and related diseases are a group of 25 rare metabolic diseases, referred to as MPS I, II, III, IV, V, VI and VII, or more commonly, by the name of the doctor who first described the condition: Hurler, Hurler Scheie, Scheie, Hunter, Sanfilippo, Morquio, Maroteaux Lamy and Sly.

Mucolipidoses and other storage diseases also covered by the Society are: MLI, MLII (I cell disease), MLIII (Pseudo Hurler Polydystrophy), MLIV, Sialidosis, Fucosidosis, Mannosidosis, Sialic Acid Storage Disease, Multiple Sulphatase Deficiency, Aspartylglycosaminuria, Winchester, Metachromatic Leukodystrophy, LaLD (Lysosomal Acid Lipase) and Fabry disease.

Children born with a 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.

OBJECTIVES AND ACTIVITIES (continued)

Public benefit

Over the reporting year the Society for Mucopolysaccharide Diseases has worked towards its charitable objectives in the best way it can but due to the COVID-19 pandemic these have had to be adapted in the following ways:

- From point of contact we have provided emotional support, practical advice, information and guidance, signposting to other resources where needed.
- All face to face visits and clinic visits have been made virtual with our Advocacy and Support team offering video call support.
- All members of our community were emailed the direct contact details of each of our Support Workers with additional out of hours contact details. This means that our community have access to our support every weekday and weekend, 7am-10pm.
- We updated our website, offering up-to-date specific guidance for those with an inherited metabolic disease and COVID-19. In addition, we are signposting to NHS and government advice.
- Delivering regular webinars to answer our communities COVID-19 questions, the first webinar held in association with the LSD collaborative was delivered to over 500 participants.
- We supported the NHS and healthcare professionals through running webinars with the Lysosomal Storage Disease (LSD) Collaborative which involve a panel of leading clinicians answering questions and providing information to support healthcare professionals to deliver infusions and treatments in the patients' homes.
- Unfortunately, we made the difficult decision to postpone all of our support events however ran a series of events and exert meetings online, more about this later.

Maintaining our external commitments to support and ensure the patients voice remains paramount with public bodies such as National Institute of Health and Care Excellence (NICE) NHS England and the European Medicines Agency (EMA)

- to be active members of the wider patient community including the UK LSD collaborative, MPS Europe and the International MPS Network
- continuing to support patients participating in clinical trials across 15 countries
- increasing our research and survey work ensuring where possible this is shared publically through posters and publications

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

Fundraising

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

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

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

ACHIEVEMENTS AND PERFORMANCE

Our priority, as ever, is to the families we support, our team, volunteers and supporters. Our commitment to ensuring that every person affected by an MPS or related disease has access to a supportive community has been more important than ever due to the COVID-19 pandemic.

Impact on our community

MPS and related diseases are multi-organ storage diseases which cause progressive physical disability and, for more than half, accelerated progressive neurological degeneration. The majority of our members are classed as more 'at risk' of COVID-19 under current NHS guidance. This is currently still having major implications on the families we support including:

- **Threat to life:** Coronavirus poses a severe threat to life for our community and, understandably, the families we support are particularly anxious about protecting their loved ones from contracting the virus. For most, this means strict self-isolation.
- **Social isolation**: Social isolation and distancing means that many of our members feel lonely and isolated. Disruption to routine can be particularly challenging for our younger members and those with neurological degeneration and/or learning disabilities. This can lead to increased challenging behaviours and outbursts for these members who are frustrated and trying to understand what is going on.
- **Limited independence:** Independence is a key issue for our members who will struggle with having to rely on others for support with everyday tasks outside the home, such as shopping, commuting, work etc., that they are used to doing themselves.
- **Challenges for parents and carers:** The majority of our community rely on parents, family and partners for their personal care. Social distancing increases care responsibilities as day groups, schools and workplaces close. Carers will now have to juggle 24/7 care responsibilities with their jobs; caring and home-schooling their other children; housework and any other responsibilities with little to no respite.
- **Disruption for siblings:** Siblings of children with an MPS or related disease are also affected. The demanding physical and emotional needs of affected members means that siblings may have to help with care, home-school alone and entertain themselves in the home. This can be particularly isolating and disruptive for younger siblings.
- **Cancelled treatments:** There is no cure for MPS and related diseases, but many members rely on regular enzyme replacement and other therapies and treatments to alleviate or reduce symptoms. With the demand on the NHS, treatments are being cancelled and our members are encouraged to not attend any 'non-essential' appointments to limit their chances of contracting the virus. This means that our member's condition may deteriorate and symptoms worsen.
- **Medical research:** The pandemic has had an impact on current and planned medical research programmes as participants will be unable to attend appointments and healthcare professionals will be drafted into Coronavirus emergency response. This will be disruptive with some research programmes being paused and others needing to be started again after the outbreak is under control.
- **NHS implications:** Where possible, those with MPS and related diseases will receive any clinical care or treatment in their own home to minimise risk of coming into contact with contagions. With the current demand on the NHS, this means that many of the healthcare professionals treating our community will be unfamiliar with this rare group of diseases. In addition, carers and parents are going to be increasingly relied on to administer some treatments, medications and injections.

Impact on our services

Due to the changing situation with the COVID-19 outbreak, the MPS Society took the decision to close our office and ask staff to work remotely from mid-March. We took steps to make sure the services we offer continued to run as normal as possible and adapted to meet the changing needs of our members during the outbreak.

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

Our vital support services for the MPS & related diseases community across 2020
Our Advocacy & Support team have continued to provide support to our community by telephone, email, and offering video calls where appropriate. Our team have continued to actively contact our membership to offer support and reassurance, to provide a listening ear in order to reduce feelings of isolation and anxiety, and to offer advice and signposting to relevant information. Since the start of the outbreak the Support and Advocacy team have been in contact with **over 1,000** individuals regarding COVID-19. This has included answering queries and concerns, ongoing case support and regular catch ups with our young people.

Events and expert meetings

- We carried out an Expert Consensus meeting on self-directed action for those with lysosomal storage diseases during times of high levels of community transmission of COVID-19. We plan to review existing literature on clinically vulnerable populations and bring together a group of expert clinicians from the UK LSD centres to share experiences, discuss the evidence and put forward recommendations for this community in the event of future high levels of transmission of coronavirus.

- In October we ran a "Rare of the Rare" online Expert Meeting featuring a range of expert speakers and 40 online delegates, exploring topics specifically relating to those we support in the ultra-rare diseases community, including Metachromatic Leukodystrophy, Multiple Sulphatase Deficiency, Fucosidosis and the Mucolipidoses. The programme included a family speaker to give their perspective on their journey through ultra-rare disease; feedback on research carried out by the Rare Disease Research Partners arm of the MPS Society into the patient experience of these diseases; diagnosis of these conditions, genetics & diagnostic testing; exploring the natural history of these diseases; best practice protocols; and breakout groups on particular topics to plan the next steps of what work can be undertaken in these areas. We are now looking at various projects to be taken forward such as clinical guidelines.

- To bring our community together and provide them with some much-needed fun and entertainment, we launched "Events for All", a series of online activities tailored to the interests of our members and their families. So far this has included an evening for a group of our bereaved families to chat together, an online Halloween party which was greatly enjoyed by around **20** of our families, and a fun Scavenger Hunt which **10** families took part in. Our "Make a Christmas decoration" event was very popular, with around **30** families attending. We sent out craft kits for the families, to follow our step-by-step guide to make the decorations with us during the session. During the festive season we ran a Christmas Quiz night, an online Christmas party and panto, and other great events which really lifted the spirits of our community.

Fundraising & Communications

Individual donations
We are very grateful to our supporters who choose to donate to us monthly. We have also received £45,414.33 donations in memory, of which £34,000 was from one family.

Do your own thing
We are grateful to our supporters who choose to fundraise for us in many creative ways throughout the year and in 2020 raised **£23,538.63**. This includes a very successful birthday fundraiser for one of our members (£1,300), Marina and Friends (a community shop with proceeds coming to MPS Society) (£6,454.72) and 60 Facebook Birthday Fundraisers (£5,705.03).

Events & Challenges
We raised **£41,233.82** from challenge events, other sports events, a supporter who is going to trek to Everest Base camp and Active April. The total from the London Marathon in 2020 was a staggering £18,786.28 even though this has to be virtual. One supporter did a solo marathon which raised £7,534.88 and an affected member raised over £1,000 for Active April.

Fundraising & Communications (continued)

Christmas Campaign
The Big Give once again was a great success with many donations coming in from supporters, companies and trusts and raised over £18k.

***MPS* Awareness Day**
Due to the pandemic our campaign was moved online and had to change direction at short notice. The week raised a total of £2,547.

Trusts & Pharmaceutical
We would like to extend a big thank you to our key supporters this year who donated emergency funds due to the pandemic, including The Gosling Foundation, Global's Make Some Noise, The Big Lottery and The Julia and Hans Rausing Trust, along with grants from a number of pharmaceutical companies. We were also very grateful to a number of charitable trusts and foundations for their grants and donations towards various aspects of our support services, including: The Masonic Charitable Foundation, the Eveson Charitable Trust, the Summerfield Charitable Trust, the Wixamtree Trust, the Pilkington Charities Fund, the Borrows Charitable Trust and the Adint Charitable Trust.

Communications
We carried out regular updates of information on our website, offering up-to-date specific guidance for those with an inherited metabolic disease and signposting to NHS and government advice, as well as regular social media posts to ensure that all of our members continued to feel part of a supportive community. Since the start of the pandemic we have had **18k** visits to the website which was a huge increase compared to the same time over previous years.

We have continued to deliver webinars to our community, providing the latest information, answering questions and building connections. We have delivered **16** webinars so far which have been very well received; one of these webinars has had **1,122** views to date on our website.

STRUCTURE, GOVERNANCE AND MANAGEMENT
Governing document
The Society is controlled by its governing document, a deed of trust, and constitutes a company, limited by guarantee, as defined by the Companies Act 2006.

The Society was founded in 1982 and was registered with the Charity Commission in 1983 as an unincorporated association, registered charity number 287034. On 2 August 2011 the Society incorporated as a company limited by guarantee with the name 'Society for Mucopolysaccharide Diseases'. The assets, liabilities and activities of the Society were transferred into this charitable company on 1 November 2011.

Recruitment and appointment of new trustees
New trustees are elected by the membership and may hold office for six years.

Induction and training of new trustees
New trustees are provided with information about the Society and its work, the role and responsibilities of trustees, and the composition and workings of the Board. They are given copies of the Society's governing instrument, a folder of all the Society's policies and the minutes of the last five Board of trustees meetings. Trustees are regularly provided with the latest information on employment and charity law through the provision of the monthly Governance and Leadership magazine.

Pay policy for key management personnel
The Board of trustees are responsible for defining the Society's pay policy and setting the annual salary for the Chief Executive.

STRUCTURE, GOVERNANCE AND MANAGEMENT (continued)

Organisational structure

The Society is governed by a Board of up to 13 trustees known as the Board of directors which meets a minimum of five times during the year. The day to day business of the Society is managed by the Chair and Vice Chair and is governed by the Articles of Association.

Wider network

One trustee's first language is Welsh and another lives in Scotland. Geographically, the MPS Society provides a UK wide support and individual advocacy service from MPS House based in Amersham in Buckinghamshire. Our 25 employees are central to providing the support, individual advocacy services and the communication of our cause, while our supporters enable us to achieve our goals and objectives.

Risk management

The trustees have identified the level of risks to which the Society may be exposed and have established the implementation of a risk management strategy which comprises quarterly reviews of the risks the Society may face, systems and procedures to mitigate these risks and implementation of procedures designed to report on and minimise any potential impact on the Society should any of these risks materialise.

The trustees have given due consideration of the recent events surrounding the outbreak of COVID-19. Whilst the economic and social impact is unknown the trustees have implemented the appropriate procedures to mitigate the impact on the Society.

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. The fundraising receipts in this reporting period were £ 114,794 compared with £93,602 in 2019. Receipts from donations and legacies were £186,832 compared with £164,170 in 2019. This year legacies of £109,377 were received whereas £16,562 legacies were received in 2019.

MPS Commercial Limited is a wholly owned trading subsidiary of the MPS Society. All logistical services related to Patient Access to Clinical Trials and work involving Health Technology Assessments and Patient Reported Outcomes are carried out by MPS Commercial. In 2020, MPS Commercial were able to donate £350,042 (2019: £416,643) to the MPS Society.

Total group income for the year ending 31 December 2020 was £2,055,446 (2019: £1,698,767) compared with total expenditure of £1,513,142 (2019: £1,581,144) resulting in a surplus of £542,304 (2019: £117,623).

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

Reserves policy

In the year, ending 31 December 2020 the trustees reviewed the charity's reserves policy to ensure that it is flexible enough to withstand the high and lows of funding, and be robust in its ability to secure the future of our services. In so doing, the trustees agreed to the established policy whereby the unrestricted funds not committed or invested in tangible fixed assets ('the free reserves') held by the charity should be six months of the unrestricted resources. In accordance with good practice, this is reviewed each year to ensure that it fairly reflects the needs of the society. The review in the current year concluded that the current policy of aiming for reserves of six months of the unrestricted resources remains appropriate. Current year our six months overall expenditure equates to £756,571 (2019: £790,572). The level of free reserves as at 31 December 2020 amounted to £745,480 (2019: £744,730) which amounts to 5.9 months of overall expenditure of the society.

PLANS FOR THE FUTURE

The MPS Society is facing unprecedented demands and pressures on the services we provide. This comes at a time when the fundraising climate is changing and increasing revenue will be challenging.

As mentioned above, we have identified that a key focus for the MPS Society for the coming two years needs to be the mental health and wellbeing of our community as this is clearly a pressing need. We want to ensure that those living with MPS and related diseases, and their families, feel better equipped to face the many difficulties of life with an MPS or related condition, particularly following the impact of the COVID-19 crisis. We want to provide tailored support and self-help techniques to affected individuals and families, leading to improved mental health and resilience. We are currently scoping out an innovative new outreach programme of support for 2021 – 2022.

Alongside the Mindfulness courses described above, we are planning to offer our members and their families the opportunity to access a series of online sessions with a professional counselling service in order for them to explore and discuss the issues they are facing and how they can work through these and face the future positively. As part of this programme of support we will explore other group activities including workshops and support groups, which would initially need to be online until it is safe to organise these in person. We are also planning to roll out surveys on mental health and wellbeing to better understand the needs of our community and how we can best meet them in ways which they will find most beneficial.

We also have exciting plans including looking at funding a psychological support post within specialised services at one of the UK specialist centres for lysosomal storage disorders, a programme of resilience work with young people living with an MPS or related condition, a programme of sibling support, advance care planning, and bereavement support.

We will continue to provide and adapt our vital support services to our community throughout the rest of the coronavirus crisis and beyond.

STATEMENT OF TRUSTEES RESPONSIBILITIES

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

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

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

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

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on MPS Society's website.

AUDITORS

In accordance with the charitable company's articles, a resolution proposing that McLintocks (NW) Limited be reappointed as auditor of the charitable company will be put at a General Meeting.

Disclosure of information to auditors

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

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

James Garthwaite, Chair of Trustees 26 June 2021
For the year ended 31 December 2020

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

Opinion

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

In our opinion the financial statements:

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

Basis for opinion

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

Emphasis of matter

We draw attention to note 24 to the financial statements which describes events after the reporting period the group and the charitable company are facing as a result of the ongoing COVID-19 pandemic. Our opinion is not modified in respect of this matter.

Conclusions relating to going concern

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

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

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

Other information

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

Other information (continued)
In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of the other information, we are required to report that fact.

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006
In our opinion, based on the work undertaken in the course of the audit:
- the information given in the Report of the Trustees, which includes the directors' report for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception
In the light of the knowledge and understanding of the environment of the charitable company and the group obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:
- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

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

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

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

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

Auditor's responsibilities for the audit of the financial statements (continued)
Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

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

The audit procedures undertaken to address any potential risk in relating to irregularities (which include fraud and non-compliance with laws and regulations) included: enquiries of management and those charged with governance on how the charitable company and group comply with relevant laws, regulations and any cases actual or potential litigation or claims; examination of appropriate legal correspondence; review of board minutes; testing of journal entries for appropriateness; and analytical procedures on account balances to identify variances against expectation which may show indications of fraud.

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

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

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

Michael Caputo FCA (Senior Statutory Auditor)
For and on behalf of McLintocks (NW) Limited

26 June 2021

Chartered Accountants
Statutory Auditor

2 Hilliards Court
Chester Business Park
Chester
Cheshire
CH4 9PX

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) for the Year Ended 31 December 2020

	Note	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
INCOME					
Voluntary income:					
Donations & legacies	3	146,265	149,944	296,209	180,732
Activities for generating funds:					
Charitable activities	4	114,794	595,310	710,104	512,817
Other trading activities	5	1,023,060	-	1,023,060	981,856
Investment income	6	26,073	0	26,073	23,362
TOTAL INCOME		1,310,192	745,254	2,055,446	1,698,767
EXPENDITURE					
Raising funds:	7				
Fundraising cost of grants & donations		75,892	-	75,892	63,563
Fundraising activities		80,405	-	80,405	74,782
Trading activities		481,193	-	481,193	542,882
		637,490	-	637,490	681,227
Charitable activities:	8				
Advocacy services & member events		12,297	475,874	488,171	720,761
Awareness raising		124,486	-	124,486	78,517
Trading activities		167,301		167,301	-
		304,084	475,874	779,958	799,278
Other costs	9	95,694	-	95,694	100,639
TOTAL EXPENDITURE		1,037,268	475,874	1,513,142	1,581,144
NET INCOMING RESOURCES		272,924	269,380	542,304	117,623
RECONCILIATION OF FUNDS					
Total funds brought forward		2,366,043	48,670	2,414,713	2,297,090
TOTAL FUNDS CARRIED FORWARD		**2,638,967**	**318,050**	**2,957,017**	**2,414,713**

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

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

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF FINANCIAL POSITION
At 31 December 2020

	Note	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
FIXED ASSETS					
Tangible assets	17	1,089,612	1,089,040	1,123,517	1,121,313
Investments	18	310,897	310,899	306,100	306,102
		1,400,509	1,399,939	1,429,617	1,427,415
CURRENT ASSETS					
Debtors	19	307,159	610,215	666,221	656,754
Cash at bank and in hand	20	2,027,320	1,007,555	851,560	429,153
		2,334,479	1,617,770	1,517,781	1,085,907
CREDITORS					
Amounts falling due within one year	21	777,971	60,692	532,685	98,609
NET CURRENT ASSETS		1,556,508	1,557,078	985,096	987,298
NET ASSETS		2,957,017	2,957,017	2,414,713	2,414,713
FUNDS	23				
Unrestricted Funds:					
General charitable funds		750,000	750,000	752,815	752,815
Property funds		1,084,520	1,084,520	1,113,228	1,113,228
Designated funds		804,447	804,447	500,000	500,000
		2,638,967	2,638,967	2,366,043	2,366,043
Restricted Funds		318,050	318,050	48,670	48,670
TOTAL FUNDS		2,957,017	2,957,017	2,414,713	2,414,713

As permitted by s408 Companies Act 2006, the charitable company has not presented its own statement of financial activities and related notes. The charitable company's surplus for the year was £542,304 (2019: £117,623).

The consolidated financial statements were approved by the Board of Trustees on 26 June 2021 and were signed on its behalf by:

.....
James Garthwaite, Chair of Trustees

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

CONSOLIDATED STATEMENT OF CASH FLOWS
for the Year Ended 31 December 2020

	Notes	2020 £	2019 £
Cash flows from operating activities:			
Cash generated from operations	1	1,185,958	(21,840)
Interest paid		(5,401)	(3,062)
Net cash provided by (used in) operating activities		**1,180,557**	(24,902)
Cash flows from investing activities:			
Purchase of tangible fixed assets		-	(8,756)
Investment in bonds		(4,797)	(300,000)
Net cash provided by (used in) investing activities		**(4,797)**	(308,756)
Change in cash and cash equivalents in the reporting period		1,175,760	(333,658)
Cash and cash equivalents at the beginning of the reporting period	2	851,560	1,185,218
Cash and cash equivalents at the end of the reporting period	2	**2,027,320**	**851,560**

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE CONSOLIDATED STATEMENT OF CASH FLOWS
for the Year Ended 31 December 2020

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

	2020 £	2019 £
Net income for the reporting period (as per the statement of financial activities)	542,304	117,623
Adjustments for:		
Interest received	5,401	3,062
Depreciation	33,385	40,930
Loss on disposal of fixed assets	520	-
Decrease/(increase) in debtors	359,063	(488,430)
Increase/(decrease) in creditors	245,285	304,975
Net cash provided by (used in) operating activities	1,185,958	(21,840)

2 ANALYSIS OF CHANGES IN NET FUNDS

	2020 £	2019 £
Cash in hand	2,289	2,472
Bank accounts	2,025,031	849,088
Total cash and cash equivalents	2,027,320	851,560

1. ACCOUNTING POLICIES

Charity information
The Society For Mucopolysaccharide Diseases is a registered charity and private company limited by guarantee incorporated in England and Wales. The registered office is MPS House, Repton Place, White Lion Road, Amersham, Buckinghamshire, HP7 9LP.

The group consists of The Society For Mucopolysaccharide Diseases and all of its subsidiaries.

The Charitable Company's financial statements have been prepared in compliance with the Charities SORP FRS 102 issued 1 January 2015 (update bulletin 2, effective 1 January 2019).

1.1 Accounting convention

The Group and Charity financial statements have been prepared in accordance with the Statement of Recommended Practice: "Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (SORP) issued on 16 July 2014 and the "Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland" (FRS 102). They also comply with the reporting requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 and the Charities Act 2011. The charitable company is a Public Benefit Entity as defined by FRS 102. The financial statements are prepared in sterling, which is the functional currency of the 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 Basis of consolidation

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

All financial statements of subsidiaries are made up to 31 December 2020.

All intra-group transactions, balances and unrealised gains on transactions between group companies are eliminated on consolidation. Unrealised losses are also eliminated unless the transaction provides evidence of an impairment of the asset transferred.

1. ACCOUNTING POLICIES (CONTINUED)

1.3 Preparation of the accounts on a going concern basis

The trustees have considered the future trading of the charitable company and the group and have prepared cash flow forecasts for a period of 12 months from the date of these financial statements.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charitable company has adequate resources to continue in operational existence for the foreseeable future, despite the COVID-19 global pandemic – see further details in note 24. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.4 Incoming resources

Income is stated after trade discounts and other sales taxes.

Voluntary income

Voluntary income, which is received by way of restricted and unrestricted donations, gifts, legacies and special fund raising events, is included in the SOFA 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 SOFA.

Investment income

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

Income from other trading activities

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

1.5 Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources. Grants payable are included in the SOFA in the year in which they relate. Grants offered subject to conditions which have not been met at the yearend date are noted as a commitment but not accrued as expenditure.

1.6 Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include Head Office costs, finance, personnel, payroll and governance costs. Governance costs are those incurred in connection with administration of the Charity and compliance with constitutional and statutory requirements. These are apportioned based on staff numbers.

1. ACCOUNTING POLICIES (CONTINUED)

1.7 Pass-through costs and reimbursements

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

1.8 Fund accounting

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

1.9 Tangible fixed assets

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

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

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

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

1.10 Fixed asset investments

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

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

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

1.11 Debtors

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

1.12 Cash at bank and in hand

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

1.13 Creditors and provisions

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

1.14 Taxation

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

1. ACCOUNTING POLICIES (CONTINUED)

1.15 Pension costs and other post-retirement benefits

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

1.16 Financial Instruments

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

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

Basic financial assets

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

Basic financial liabilities

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

Derecognition of financial liabilities

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

1.17 Critical accounting estimates and judgements

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

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

2. LEGAL STATUS

The Charity is a company limited by guarantee. The members of the company are the trustees named on page 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.

3. DONATIONS AND LEGACIES

	2020 Unrestricted fund £	2020 Restricted fund £	2020 Total funds £	2019 Unrestricted fund £	2019 Restricted fund £	2019 Total funds £
Donations	146,265	40,567	186,832	164,170	-	164,170
Legacies	-	109,377	109,377	16,562	-	16,562
	146,265	149,944	296,209	180,732	-	180,732

4. INCOME FROM CHARITABLE ACTIVITIES

	2020 Unrestricted fund £	2020 Restricted fund £	2020 Total funds £	2019 Total funds £
Advocacy support grants	93,194	561,810	655,004	236,465
Conferences and Expert meetings	-	33,500	33,500	157,750
Family support special events	11,600	-	11,600	25,000
Fundraising events	-	-	-	91,845
Other income	10,000	-	10,000	1,757
	114,794	595,310	710,104	512,817

INCOME FROM CHARITABLE ACTIVITIES – 2019 COMPARATIVES

	2019 Unrestricted fund £	2019 Restricted fund £	2019 Total funds £
Advocacy support grants	-	236,465	236,465
Conferences and Expert meetings	-	157,750	157,750
Family support special events	-	25,000	25,000
Fundraising events	91,845	-	91,845
Other income	1,757	-	1,757
	93,602	419,215	512,817

5. OTHER TRADING ACTIVITIES

	2020 £	2019 £
Survey income in subsidiary	288,928	259,400
Management fees in subsidiary	733,316	720,988
Miscellaneous trading	816	1,468
	1,023,060	981,856

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

6. INVESTMENT INCOME

	2020	2019
	£	£
Rent receivable	20,672	20,300
Interest receivable	5,401	3,062
	26,073	23,362

All investment income is recorded in the unrestricted fund.

7. EXPENDITURE ON RAISING FUNDS

	Note	Fundraising Grants & Donations	Fundraising Events	Commercial Trading Activity	Total 2020	Total 2019
		£	£	£	£	£
Staff costs	15	24,080	44,977	390,369	459,426	456,252
Direct costs	10	32,475	16,092	59,286	107,853	86,041
Depreciation	11	3,227	3,226	1,111	7,564	10,506
Support costs	11	16,110	16,110	30,427	62,647	128,428
		75,892	80,405	481,193	637,490	681,227
Attributable to:						
Unrestricted funds		75,892	80,405	481,193	637,490	681,227
Restricted funds		-	-	-	-	-
		75,892	80,405	481,193	637,490	681,227

EXPENDITURE ON RAISING FUNDS – 2019 COMPARATIVES

	Note	Fundraising Grants & Donations	Fundraising Events	Commercial Trading Activity	Total 2019
		£	£	£	£
Staff costs	15	27,113	33,414	395,725	456,252
Direct costs	10	14,754	19,672	51,615	86,041
Depreciation	11	3,803	3,803	2,900	10,506
Support costs	11	17,893	17,893	92,642	128,428
		63,563	74,782	542,882	681,227
Attributable to:					
Unrestricted funds		63,563	74,782	542,882	681,227
Restricted funds		-	-	-	-
		63,563	74,782	542,882	681,227

8. EXPENDITURE ON CHARITABLE ACTIVITIES

	Note	Advocacy & Members Events	Awareness Raising	Commercial Trading Activity Patient Support	Total 2020	Total 2019
		£	£		£	£
Staff costs	15	296,353	83,099	167,301	546,753	423,187
Direct costs	10	85,733	12,383	-	98,116	235,070
Research grants	12	9,400	-	-	9,400	-
Depreciation	11	16,139	4,841	-	20,980	24,719
Support costs	11	80,546	24,163	-	104,709	116,302
		488,171	124,486	167,301	779,958	799,278
Attributable to:						
Unrestricted funds		12,297	124,486	167,301	304,084	353,313
Restricted funds		475,874	-	-	475,874	445,965
		488,171	124,486	167,301	779,958	799,278

EXPENDITURE ON CHARITABLE ACTIVITIES – 2019 COMPARATIVES

	Note	Advocacy & Members Events	Awareness Raising	Total 2019
		£	£	£
Staff costs	15	391,968	31,219	423,187
Direct costs	10	220,316	14,754	235,070
Depreciation	11	19,014	5,705	24,719
Support costs	11	89,463	26,839	116,302
		720,761	78,517	799,278
Attributable to:				
Unrestricted funds		445,965	78,517	353,313
Restricted funds		274,796	-	445,965
		720,761	78,517	799,278

9. OTHER EXPENDITURE

	Note	Management & Governance 2020 £	Total 2020 £	Management & Governance 2019 £	Total 2019 £
Staff costs	15	49,816	49,816	45,008	45,008
Direct costs	10	16,873	16,873	23,087	23,087
Depreciation	11	4,841	4,841	5,705	5,705
Support costs	11	24,164	24,164	26,839	26,839
		95,694	95,694	100,639	100,639
Attributable to:					
Unrestricted funds		95,694	95,694	100,639	100,639
Restricted funds		-	-	-	-
		95,694	95,694	100,639	100,639

10. ALLOCATION OF DIRECT COSTS

	Note	Total Funds 2020 £	Total Funds 2019 £
Advocacy travel		3,210	25,157
Conference and expert meetings		6,196	155,999
Support events		59,456	21,987
Communications		12,383	13,557
MPS awareness		-	14,754
Fundraising expenses		16,092	34,425
Donations and tributes in memory		3,208	901
Management & Governance		16,873	23,088
Survey costs		59,286	52,336
LSD collaborative		833	1,994
Grant consultancy costs		32,475	-
Patient welfare gifts		12,830	-
		222,842	344,198
Attributable to raising funds	7	107,853	86,041
Attributable to charitable activities	8	98,116	235,070
Attributable to other costs	9	16,873	23,087
		222,842	344,198

11. ALLOCATION OF SUPPORT COSTS

	Note	2020	2019
		£	£
Recruitment & training costs		10,566	9,524
General office expenses		91,647	104,242
Insurance		11,180	6,235
Subscriptions		432	5,669
Staff welfare		10,081	8,417
Computer expenses and software		32,469	34,980
Professional fees		7,812	8,951
Bank charges		5,887	3,439
Bad debts		42	1,001
Travel and subsistence		485	23,662
Consultancy expenses		13,499	57,758
Auditors remuneration		6,900	7,690
Depreciation		33,385	40,930
Loss on disposal of asset		520	-
		224,905	312,499
Attributable to raising funds	7	70,211	138,934
Attributable to charitable activities	8	125,689	141,021
Attributable to other costs	9	29,005	32,544
		224,905	312,499

12. GRANTS PAYABLE

	2020	2019
	£	£
Grants and donations	9,400	-

Grants payable to institutions

	2020	2019
	£	£
Salford Royal NHS Foundation Trust	9,400	-

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

13. NET INCOME/(EXPENDITURE)

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

	2020	2019
	£	£
Auditors' remuneration	6,900	7,500
Depreciation	33,385	40,930

14. TRUSTEES' REMUNERATION AND BENEFITS

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

All trustees are reimbursed for their expenses or expenses are paid for by the charity on behalf of trustees, which are necessarily incurred in attending management committee meetings and in performing their duties as trustees. The Chief Executive Officer of the Society approves the reimbursement of such expenses. In 2020 these totalled £2,044 (2019: £5,300) for all trustees.

15. STAFF COSTS

	Group		Charity	
	2020	2019	2020	2019
	£	£	£	£
Wages and salaries	924,436	817,477	439,017	468,536
Social security costs	88,881	76,586	38,114	41,697
Other pension costs	42,677	30,384	21,193	18,488
	1,055,994	924,447	498,324	528,721

The allocation of pension costs between funds follows the allocation of the associated employee remuneration.

The average monthly number of employees during the year was as follows:

	Group		Charity	
	2020	2019	2020	2019
	£	£	£	£
Director	2	2	1	1
Administration	3	3	3	3
Advice, information & support	14	15	14	15
Commercial trading operation	11	9	-	-
	30	29	18	19

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

	Group		Charity	
	2020	2019	2020	2019
	£	£	£	£
In the band £80,001 - £90,000	-	1	-	1
In the band £90,001 - £100,000	1	-	1	-
In the band £120,001 - £130,000	1	-	-	-
	2	1	1	1

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 £418,876 (2019: £305,849). The highest paid director of the charity had accrued £4,701 (2019: £3,553) in employer pension contributions and the highest paid director of the group had accrued £6,375 (2019: £1,042) in employer pension contributions.

16. 2019 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Note	Unrestricted funds £	Restricted funds £	2019 Total funds £	2018 Total funds £
INCOME					
Voluntary income:					
Donations & legacies	3	180,732	-	180,732	144,477
Activities for generating funds:					
Charitable activities	4	93,602	419,215	512,817	634,878
Other trading activities	5	981,856	-	981,856	685,685
Investment income	6	23,362	-	23,362	37,613
TOTAL INCOME		1,279,552	419,215	1,698,767	1,502,653
EXPENDITURE					
Raising funds:	7				
Fundraising grants & donations		63,563	-	63,563	61,628
Fundraising activities		74,782	-	74,782	61,152
Trading activities		542,882	-	542,882	440,093
		681,227	-	681,227	562,873
Charitable activities:	8				
Advocacy services & member events		274,796	445,965	720,761	604,068
Awareness raising		78,517	-	78,517	31,509
		353,313	445,965	799,278	635,577
Other costs		100,639	-	100,639	95,727
TOTAL EXPENDITURE		1,135,179	445,965	1,581,144	1,294,177
NET INCOME / (EXPENDITURE)		144,373	(26,750)	117,623	208,476
RECONCILIATION OF FUNDS					
Total funds brought forward		2,221,670	75,420	2,297,090	2,088,614
TOTAL FUNDS CARRIED FORWARD		**2,366,043**	**48,670**	**2,414,713**	**2,297,090**

17. TANGIBLE FIXED ASSETS

Group	Freehold Land and buildings	Plant and Equipment	Totals
	£	£	£
COST			
At 1 January 2019	1,435,389	269,840	1,705,229
Additions	-	-	-
Disposals	-	(212,073)	(212,073)
At 31 December 2020	1,435,389	57,767	1,493,156
DEPRECIATION			
At 1 January 2019	322,160	259,552	581,712
Charge for year	28,709	4,676	33,385
Eliminated on disposal	-	(211,553)	(211,553)
At 31 December 2020	350,869	52,675	403,544
NET BOOK VALUE			
At 31 December 2020	1,084,520	5,092	1,089,612
At 31 December 2019	1,113,229	10,288	1,123,517

Charity	Freehold Land and buildings	Plant and Equipment	Totals
	£	£	£
COST			
At 1 January 2019	1,435,389	221,636	1,657,025
Additions	-	-	-
Disposals	-	(172,575)	(172,575)
At 31 December 2020	1,435,389	49,061	1,484,450
DEPRECIATION			
At 1 January 2019	322,160	213,552	535,712
Charge for year	28,709	3,564	32,273
Eliminated on disposal	-	(172,575)	(172,575)
At 31 December 2020	350,869	44,541	395,410
NET BOOK VALUE			
At 31 December 2020	1,084,520	4,520	1,089,040
At 31 December 2019	1,113,229	8,084	1,121,313

18. FIXED ASSET INVESTMENTS

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Shares in subsidiary	-	2	-	2
Donated jewellery	6,100	6,100	6,100	6,100
Investments in bank bonds	304,797	304,797	300,000	300,000
	310,897	310,899	306,100	306,102

Investment in subsidiaries

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

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

	MPS Commercial Limited		Rare Disease Research Partners Limited	
	2020	2019	2020	2019
		£	£	£
Fixed assets	572	2,203	-	-
Current assets	1,318,376	1,046,602	1	1
Current liabilities	(1,318,947)	(1,048,804)	-	-
Aggregate share capital and reserves	1	1	1	1
Net income from trading activities	350,042	416,643	-	-

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 £304,947 in fixed business bonds, which are due to mature within less than one year. Of the £304,947 invested, £200,000 has been allocated to the designated fund - £150,000 for the Research Fund and £50,000 for the Service Development Fund.

19. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Trade debtors	249,503	20	592,495	127
Amounts owed by group undertakings	-	601,667	-	616,642
Other debtors	51,387	2,259	55,446	25,824
Prepayments	6,269	6,269	18,280	14,160
	307,159	610,215	666,221	656,753

20. CASH AT BANK AND IN HAND

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Cash held in parent charity	1,007,555	1,007,555	429,513	429,513
Cash held in subsidiary	1,019,765	-	422,407	-
	2,027,320	1,007,555	851,560	429,153

21. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 Group £	2020 Charity £	2019 Group £	2019 Charity £
Trade creditors	16,282	5,337	76,014	11,392
Other creditors	753,259	48,755	442,307	80,522
Accrued expenses	8,430	6,600	14,364	6,695
	777,971	60,692	532,685	98,609

Included within other creditors is deferred income of £209,653 (2019: £353,853). Deferred income is recognised in MPS Commercial where administration fees for patients are spread accordingly with their associated period. Deferred income in The Society For Mucopolysaccharide Diseases is recognised in respect of grants where the performance agreement runs across multiple periods. All of the deferred income recognised in 2019 has been subsequently recognised as income in 2020.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	2020 Unrestricted funds £	2020 Restricted funds £	2020 Total Funds £	2019 Unrestricted funds £	2019 Restricted Funds £	2019 Total Funds £
Fixed assets	1,089,613	-	1,089,613	1,123,517	-	1,123,517
Investments	310,897		310,897	306,100	-	306,100
Current assets	2,016,428	318,050	2,334,478	1,469,111	48,670	1,517,781
Current liabilities	(777,971)		(777,971)	(532,685)	-	(532,685)
	2,638,967	318,050	2,957,017	2,366,043	48,670	2,414,713

23. STATEMENT OF FUNDS

Group

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

Charity

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

23. STATEMENT OF FUNDS (CONTINUED)
2019 COMPARITIVES

Group

	Funds at 1 January 2019	Income	Expenditure	Fund Transfers	Funds at 31 December 2019
Unrestricted funds					
General charitable fund	779,734	1,237,832	(1,064,751)	(200,000)	752,815
Property fund	1,141,936	-	(28,708)	-	1,113,228
Designated funds					
Research fund	100,000	41,720	(41,720)	150,000	250,000
Service development fund	100,000	-	-	50,000	150,000
Building refurbishment fund	100,000	-	-	-	100,000
	300,000	41,720	(41,720)	200,000	500,000
Total unrestricted funds	2,221,670	1,279,552	(1,135,179)	-	2,366,043
Restricted funds					
MPS restricted fund	56,677	419,215	(443,971)	-	31,922
LSD restricted fund	18,743	-	(1,994)	-	16,749
Total restricted funds	75,420	419,215	(445,965)	-	48,670
Total Funds	**2,297,090**	**1,698,767**	**(1,581,144)**	**-**	**2,414,713**

Charity

	Funds at 1 January 2019	Income	Expenditure	Fund Transfers	Funds at 31 December 2019
Unrestricted funds					
General charitable fund	779,734	695,588	(522,507)	(200,000)	752,815
Property fund	1,141,936	-	(28,708)	-	1,113,228
Designated funds					
Research fund	100,000	41,720	(41,720)	150,000	250,000
Service development fund	100,000	-	-	50,000	150,000
Building refurbishment fund	100,000	-	-	-	100,000
	300,000	41,720	(41,720)	200,000	500,000
Total unrestricted funds	2,221,670	737,308	(592,935)	-	2,366,043
Restricted funds					
MPS restricted fund	56,677	419,215	(443,971)	-	31,921
LSD restricted fund	18,743	-	(1,994)	-	16,749
Total restricted funds	75,420	419,215	(445,965)	-	48,670
Total Funds	**2,297,090**	**1,156,523**	**(1,038,900)**	**-**	**2,414,713**

23. STATEMENT OF FUNDS (CONTINUED)

Restricted funds

MPS restricted fund – to support Disease booklets and Advocacy services.
LSD restricted fund – to support Lysosomal Storage Disease related meetings and conferences.
Research restricted fund – to support MPS research related projects

Designated funds

Research fund – to support MPS research related projects.
Service development fund – to develop MPS new service for members.
Building refurbishment fund – to maintenance of MPS House.
Christine Lavery memorial fund – to support Christine Lavery's memorial charitable events

24. EVENTS AFTER THE REPORTING DATE

At the balance sheet date, the World Health Organization had declared the outbreak of COVID-19, a novel strain of coronavirus, a pandemic. The coronavirus outbreak is disrupting supply chains and affecting production and sales across a range of industries. However, despite COVID-19, the group and charity are fully operational and have considered the potential impact of COVID-19 on their operations, risk management and financial forecasts for the period of one year from the date of signing of the financial statements.

As a result of the assessment, the trustees consider that the group and the charity have adequate resources to continue in operational existence for a period of twelve months from signing of the financial statements.

As a result of the assessment of the events and conditions summarised above and based on information available at the date of approval of the financial statements, the group and charity have concluded that there are no material impacts in relation to the COVID-19 pandemic.

The trustees have confirmed there are no other events after the reporting period that are required to be disclosed.

25. RELATED PARTY DISCLOSURES

MPS Commercial Limited and Rare Disease Research Partners Limited are 100% owned subsidiaries of The Society for Mucopolysaccharide Diseases.

Included in other debtors within the charitable company is the intercompany balance of £601,667 (2019: £616,642). All the profits of MPS Commercial Limited for the period have been distributed by Gift Aid to the Charity. The profits for the year total £350,042 (2019: £416,643).

Rent and recharges of £20,000 (2019: £16,000) 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 (2019: £200,000) on which interest of £4,525 (2019: £5,500) was charged.

During the year the charitable company incurred £39,546 (2019: £nil) in consultancy costs with Harvey Pharma Consulting Ltd, a company in which trustee Mr G Harvey is a director. At 31 December 2020 there was a balance of £nil (2019: £nil) due to the related party.

No donations were received from trustees or related parties.

26. ULTIMATE CONTROLLING PARTY

The board of trustees controls the charity.