

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES REPORT OF THE TRUSTEES AND AUDITED CONSOLIDATED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2018



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



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REFERENCE AND ADMINISTRATIVE DETAILS for the Year Ended 31 December 2018

Trustees & Directors

Judith Mary Evans Reappointed 13 April 2018
Paul Moody Resigned 29 September 2018

Jessica Clare Kafizas Resigned 28 December 2018

Wilma Anne Robins

Tim John Summerton Resigned 31 December 2018

Bryan Gordon Winchester Kaur Sukhvinder Bhachu

Daniella Lisa Vandepeer Resigned 31 January 2019

David Maurice Patton James Henry Garthwaite

James Henry Garthwaite Appointed 13 April 2018
Robert Gordon Harvey Appointed 15 February 2019
Bhanu Atul Mehta Appointed 15 February 2019
John Philip Pearson Appointed 15 February 2019

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

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

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

The trustees who are also the directors of the charity for the purposes of the Companies Act 2006 present their report with the audited financial statements of the charity for the year ended 31 December 2018. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) applicable to charities preparing their accounts in accordance with the Financial Reporting Standard (FRS 102) (effective 1 January 2015).

INTRODUCTION

The last 12 months have been a period of significant change for Team MPS. It has been a time of renewed optimism and determination to build upon the legacy that Christine Lavery, our founder, left us. The year started as Bob Stevens, appointed Group CEO at the end of 2017, took the helm.

During 2018, we made investments in the charity to equip it for the future. Appointments were made to strengthen the staff team with clinical, financial and fundraising expertise. We also invested in a new database which enables us to work more effectively and in compliance with the General Data Protection Regulation (GDPR). This is helping the team offer a more efficient service.

We are proud of the difference that we continue to make to those living with MPS, Fabry and related diseases. Our advocacy team is at the core of everything the charity delivers. From the point of diagnosis, it provides a unique, flexible, care and support service to its members which is wide ranging and diverse.

In September, we launched our "Vision Project" in order to get closer to members. This is the largest consultation in our history and has helped us understand what our families, clinicians and other key stakeholders want from Team MPS in the future. It captured a wide range of opinions and ideas from all corners and we are busy turning this in to the new three year business plan. This plan will be launched at the Family Conference at the Hilton Coventry on 28th-30th June 2019.

The team also successfully introduced some new-look events including Expert Meetings for MPS I and MPS II in April, and a bereaved families' weekend in October. All three were well attended and enjoyed very positive feedback, giving us fresh ideas for the future.

Importantly, the charity made a surplus during the year, helped by the launch of The Christine Lavery Memorial Fund in January and the performance of MPS Commercial, our wholly owned business which provides services to the rare disease community. This surplus has enabled us to allocate funds for clinical research.

It is worth noting that the Society for Mucopolysaccharide Diseases (MPS Society) continues to play an essential role within the Lysosomal Storage Disease (LSD) community in the UK via the LSD Collaborative, Bob Stevens being Vice Chair and internationally as part of the Fabry International Network, MPS Europe and as Co-Chair of the International MPS network. Working together globally with our partners we are raising awareness of these rare diseases and continuing to campaign for access to new treatments and therapies for all those affected, giving a voice to those who previously were unheard.

While we continue to see progress in new treatments, there are challenges ahead both in the political and the funding arenas. Fortunately, the Society has a strong team in place and an excellent reputation which we believe will help us achieve better outcomes.

On behalf of the trustees and families, I would like to thank the entire staff team for the remarkable work they did during the year and for their continued commitment.

James Garthwaite, Chair of Trustees

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

OBJECTIVES AND ACTIVITIES

Principal activity

To support individuals affected by Mucopolysaccharide disease, 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

- to provide support to individuals affected by Mucopolysaccharide and related lysosomal storage diseases, their families and the professionals who care for them
- to increase awareness of Mucopolysaccharide and related lysosomal storage diseases amongst health, social care and education professionals
- to extend this to the community at large to secure improved local services and inclusion for affected children and adults and their families
- to raise funds for research into Mucopolysaccharide and related lysosomal storage diseases that may lead to improved clinical care, quality of life and new therapies

In order to carry out these objectives:

- we research the needs of children and adults affected by MPS and related lysosomal storage diseases
- we fund cutting-edge, peer-reviewed research that may lead to therapeutic options for those affected
- · we campaign for change in government policy and practice
- we deliver services to those affected by MPS and related lysosomal storage diseases
- we operate in the four countries of the United Kingdom and collaborate with MPS patient organisations throughout Europe and the rest of the world, to raise awareness and seek ways to grow income

To achieve these objectives, we rely on:

- funding from voluntary donations, corporate donors, charitable trusts and statutory bodies
- 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.

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

OBJECTIVES AND ACTIVITIES - continued

Public benefit

Over the reporting year MPS has worked towards its charitable objectives in the following ways:

- from point of contact we have provided emotional support, practical advice, information and guidance, signposting to other resources where needed
- we have kept to our commitment to have more face to face contact with our members, seeing a 26% increase in visits since 2017
- holding the first patient expert meeting for MPS I and MPS II in Northampton
- 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
- investing in ourselves, undertaking a cross sectional study to inform our future aims and objectives, improving our communication streams and updating our Customer Relationship Management (CRM) system
- undertaking the "Vision Project" which involved many of our key stakeholders and has led to the development of our new 2019-2021 strategy and business plan.
- continuing to support patients participating in clinical trials across 15 countries
- increasing our research and survey work ensuring where possible this is share publically through posters and publications
- as part of our objective to support families impacted by our diseases, we held our second weekend for bereaved families in Nottingham

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 Income Generation and 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.

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

ACHIEVEMENTS AND PERFORMANCE

The rarity of MPS and related lysosomal conditions means that access to clinical specialists, accurate information, treatment possibilities and links with other individuals and families, can sometimes be limited without our support, guidance and interventions.

The MPS Society's Advocacy and Support services provide a unique, flexible caring service which is not just restricted to individual sufferers but is extended to their families and professionals. We work in partnership with individuals, families, health, social care and educational professionals ensuring that the individual and their needs always remains our main priority and focus.

From point of contact the support team provide emotional support, practical advice, information and guidance, signposting to other resources where needed. The team look at needs and abilities independent of statutory support services. The team assess and advocate for the services taking on a needs led attitude and approach to ensure services and support are tailored to the individual at all times.

The current areas of support being provided include but are not exclusive to the following:

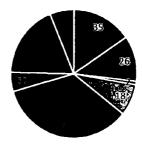
Core Support Areas	Additional Support and Involvement
 Telephone helpline / Out of hours service New diagnosis / membership Disability benefits Housing and equipment Education / school talks Respite care Independent living / transition Clinical management Befriending service Events, clinics, conferences, information days Bereavement support 	 Legal support Surveys Research Clinical trials Campaigning Mediation Homecare Policies Medical guidelines / processes Publications Special Projects Corporate fundraising Fundraising Training / Presentations Registry information

Advocacy Team In Numbers

Days out of the office for visiting patients 246 days out of the office Average 20.5 days per month / 4.7 per week

Hours out of the office for visiting patients 1,704.75 hours out of the office Average 142hrs per month / 33hrs per week

Number of visits split per area of the country

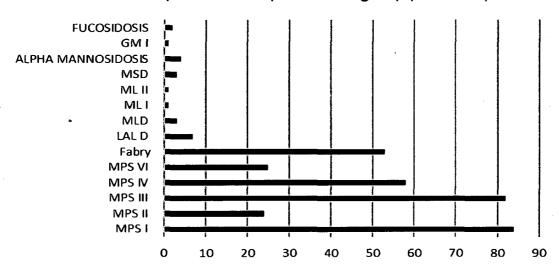


- West Midlands
- Wales
- South east / London
- North West
- South West
- North East
- East Anglia
- East midlands

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

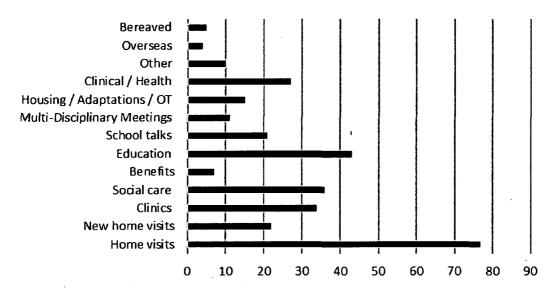
ACHIEVEMENTS AND PERFORMANCE - continued

Number of patients seen per disease group (Total 348)



In 2017 there were 277 visits to families/clinics compared to 312 visits/meetings in 2018. This shows a 12.6% increase in demand for our services compared to 2017. Average mileage visiting families totalled 2,653 (£1,194).

Number of visits / meetings per area of need (Total 312)



REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

ACHIEVEMENTS AND PERFORMANCE – continued

Advocacy Team

There were changes in the Advocacy and Support team structure in early 2018. The role of Head of Advocacy and Patient Services was created and a new Advocacy Support Lead was appointed. We also appointed a Senior Advocacy Support Officer. The main aim for 2018 was to ensure sustainability of the advocacy service in the uncertain financial climate of 2018 and with the sudden loss of the MPS Society's CEO, Christine Lavery.

The Advocacy and Support team maintained external commitments to support and ensure the patients voice in areas including NICE and EMA and we participated in patient advisory meetings and LSD nurse meetings in order to share ideas on joint projects to improve patient outcomes.

The Southern Irish MPS community were supported by our Advocacy & Support Officer based at Belfast Hospital and as part of this support ensured that access to the treatment Vimizim for MPS IV patients was offered. In-person visits to patients in Southern Ireland were gradually reduced but support over the telephone and in writing were still offered.

A number of events were held throughout the year for our families. These included expert patient meetings for our MPS I and MPS II families, a therapeutic recreation camp called Over the Wall for Fabry members, which was supported by the advocacy team, a weekend for our bereaved families including planting memorials at the MPS Childhood Wood and at Christmas we held a family event at Glenarm Castle in Northern Ireland and a family trip to Lapland UK. The team also attended the International MPS symposium, USA and collaborated with other LSD organisations on a key campaign around childhood dementia.

Fundraising and Communications

Our supporters

Last year we raised £153k from our supporters up and down the country with following highlights:

- Events and challenges our supporters climbed, ran, jumped, cycled, walked and swam throughout 2018. Our team of 5 London marathon runners completed the iconic challenge and raised £26k.
- Individuals last year many individuals supported us by making a regular donation raising a total of £5,500.
- Christmas campaign our Christmas campaign raised £3,300, a great achievement for the first time we have attempted an appeal at Christmas time.

MPS Awareness Day

A key highlight to the year was MPS Awareness Day. Information on MPS and related diseases was seen 5,781 times on social media and resulted in 62 new Facebook followers. Interviews with 20 MPS families were shared in a number of broadcast outlets which reached 20 million listeners. We are so grateful to everyone who got involved with the awareness campaign.

Trusts and Pharmaceutical

The Gosling Foundation, The Shauna Gosling Trust, Eveson Charitable Trust and Baily Thomas Charitable Fund are among many grant-making trusts and foundations which have supported the charity in 2018. Grants were also obtained from a number of pharmaceutical companies.

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

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.

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 Chairman and Vice Chairman and is governed by the Articles of Association. There is a Financial Oversight Committee that meets as needed.

Wider network

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.

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

STRUCTURE, GOVERNANCE AND MANAGEMENT - continued

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.

Charity governance code

MPS take good governance very seriously and the charity governance code represents a standard of good governance practise to what we should aspire. The code develops the seven principles of leadership, integrity, decision making, risk and control, board effectiveness, diversity and openness and accountability, MPS embrace these. The charity itself does not claim to be fully compliant yet but the gaps have been identified and are being addressed so MPS are striving towards full compliance.

FINANCIAL REVIEW

The MPS Society continues to raise and receive funds through applications to grant giving bodies to support its advocacy service, 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 unrestricted income by way of donations and fundraising. The fundraising receipts in this reporting period were £166,242 compared with £134,161 in 2017. Receipts from general donations and legacies were £144,477 compared with £74,820 in 2017. This year legacies of £50,800 were received whereas no legacies were received compared in 2017.

MPS Commercial Limited is a wholly owned not for profit 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 2018 MPS Commercial were able to make a donation of £231,788 to the MPS Society.

Total group income for the year ending 31 December 2018 was £1,502,653 compared with expenditure of £1,294,177 resulting in a surplus of £208,476.

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 ended 31 December 2018 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; this equates to £647,089 (2017: £700,618). The Governing Council considers at this level the Society would be able to continue the current activities of the charity with the reserves covering the net funding requirements for the provision of services and for events put on by the Society to raise funds in the event of a short-term reduction in income generating activities.

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

FINANCIAL REVIEW - continued

Reserves policy - continued

The level of free reserves as at 31 December 2018 amounted to £765,980 (2017: £839,537) which equates to 7 months of unrestricted resources.

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. The trustees also recognise that in order to meet these challenges the Society needs to undertake a programme of inward investment. We will continue to put our members & their families at the forefront of what we do and provide a unique, flexible care and support service which is wide ranging and diverse. Over the next 3 years we will:

- ensure a high quality service to individuals with MPS & related diseases and their families
- extend our range and scope of support offered to individuals and families
- raise more funds to ensure we can maintain and develop our support for families
- increase our public awareness

The above initiatives will have an impact on the overall financial situation of the Society in 2018 and the trustees have set budgets accordingly. Grant funding will be sought wherever possible and other new fundraising initiatives will be introduced during the period. The measures outlined above will enable the Society to ensure its long term sustainability and will provide the opportunity for future growth.

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 Report of the Trustees and the financial statements in accordance with applicable law and Financial Reporting Standards (FRS102). The trustees have adopted the provisions of 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 2015).

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;
- 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 proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company 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.

REPORT OF THE TRUSTEES for the Year Ended 31 December 2018

STATEMENT OF TRUSTEES RESPONSIBILITIES - continued

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.

AUDITORS

The auditors, McLintocks (NW) Limited, will be proposed for re-appointment at the forthcoming Annual General Meeting. Approved by order of the board of trustees on 28th June 2019 and signed on its behalf by:

James Garthwaite, Chair of Trustees

REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES AND MEMBERS OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Opinion

We have audited the financial statements of Society for Mucopolysaccharide Diseases (the 'charitable company') and its subsidiary for the year ended 31 December 2018 on pages 15-32. 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 Financial Reporting Standard 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 charitable company's affairs as at
 31 December 2018 and of its income and expenditure for the year then ended; and
- 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 and have been prepared in accordance with the Charities SORP 2015.

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 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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and 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, 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.

REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES AND MEMBERS OF 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 for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- 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 charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006, the Charities (Accounts and Reports) Regulations 2008 and the Charities Accounts (Scotland) Regulations 2006 (as amended) 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.

Responsibilities of trustees

As explained more fully in the Statement of Trustees Responsibilities set out on page eight, the trustees (who are also the directors of the charitable company for the purposes 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

We have been appointed as auditors under section 144 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 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 a Report of the Independent Auditors 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.

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/auditors responsibilities. This description forms part of our Report of the Independent Auditors.

REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES AND MEMBERS OF SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with part 4 of the Charities (Accounts and Reports) Regulations 2008, regulation 10 of the Charities Accounts (Scotland) Regulations 2006 and 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

for and on behalf of McL Chartered Accountants Statutory Auditors 2 Hilliards Court Chester Business Park Chester CH4 9PX

28th June 2019

STATEMENT OF CONSOLIDATED FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) for the Year Ended 31 December 2018

		Unrestricted funds	Restricted funds	2018 Total funds	as restated 2017 Total funds
	Note	£	£	£	£
INCOME					
Voluntary income:					
Donations & legacies	3	144,477	-	144,477	74,820
Activities for generating funds:					
Charitable activities	4	161,598	473,280	634,878	661,703
Other trading activities	5	685,685	-	685,685	547,160
Investment income	. 6	37,613	-	37,613	51,548
TOTAL INCOME	-	1,029,373	473,280	1,502,653	1,335,231
EXPENDITURE					
Raising funds:	7				
Fundraising grants & donations	-	61,628	-	61,628	69,200
Fundraising activities		61,152	-	61,152	81,686
Trading activities		440,093	-	440,093	332,676
	-	562,873	•	562,873	483,562
Charitable activities:	8				
Advocacy services & member events		148,966	455,102	604,068	791,155
Awareness raising		31,509	-	31,509	34,654
	-	180,475	455,102	635,577	825,809
Other costs		95,727	-	95,727	91,864
TOTAL EXPENDITURE	-	839,075	455,102	1,294,177	1,401,235
NET INCOME / (EXPENDITURE)					
BEFORE TRANSFERS		190,298	18,178	208,476	(66,004)
Transfers between Funds	-	(5,996)	5,996	-	-
NET INCOME / (EXPENDITURE)		184,302	24,174	208,476	(66,004)
RECONCILIATION OF FUNDS					
Total funds brought forward		2,037,368	51,246	2,088,614	2,154,618
TOTAL FUNDS CARRIED FORWARD	, -	2,221,670	75,420	2,297,090	2,088,614

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 compromises with the requirements for an income and expenditure account under the Companies Act 2006.

CONSOLIDATED STATEMENT OF FINANCIAL POSITION At 31 December 2018

FIXED ASSETS Tangible assets Investments	Notes 16 17	2018 Group £ 1,155,691 6,100 1,161,791	2018 Charity £ 1,152,300 6,101 1,158,401	as restated 2017 Group £ 1,197,831 6,100 1,203,931	2017 Charity £ 1,189,392 6,101 1,195,493
CURRENT ASSETS Debtors Cash at bank and in hand	18 19	177,791 1,185,218 ————————————————————————————————————	559,217 598,234 ————————————————————————————————————	192,671 1,716,652 1,909,323	455,228 914,738 1,369,966
CREDITORS Amounts falling due within one year NET CURRENT ASSETS	20	227,710	18,762	744,640	196,844 1,173,121
TOTAL ASSETS LESS CURRENT LIABILITIES		2,297,090	2,297,091	2,368,614	2,368,615
CREDITORS Amounts falling due after more than one year NET ASSETS	21	2,297,090	2,297,091	280,000	280,000 2,088,615
FUNDS Unrestricted Funds:	24				
General charitable funds Designated funds Property funds		779,734 300,000 1,141,936	779,735 300,000 1,141,936	866,723 - 1,170,645	866,724 - 1,170,645
Restricted Funds		75,420	75,420	51,246	51,246
TOTAL FUNDS		2,297,090	2,297,091	2,088,614	2,088,615

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

The consolidated financial statements were approved by the Board of Trustees on 28th June 2019 and were signed on its behalf by:

James Garthwaite - Trustee

CONSOLIDATED STATEMENT OF CASH FLOWS for the Year Ended 31 December 2018

N	lotes	2018 £	2017 £
Cash flows from operating activities: Cash generated from operations Interest paid	1	(109,400) <u>(8,816</u>)	321,081 (13,525)
Net cash provided by (used in) operating activities		118,216	307,556
Cash flows from investing activities: Purchase of tangible fixed assets		<u>(7,034</u>)	(28,941)
Net cash provided by (used in) investing activities		(7,034)	(28,941)
Cash flows financing Amounts repaid on borrowings		<u>(406,184</u>)	(21,475)
Net cash provided by (used in) financing		(406,184)	(21,475)
Change in each and each equivalents in			
Change in cash and cash equivalents in the reporting period		(531,434)	257,140
Cash and cash equivalents at the beginning of the reporting period	2	1,716,652	1,459,512
Cash and cash equivalents at the end of the reporting period	2	1,185,218	1,716,652

NOTES TO THE CONSOLIDATED STATEMENT OF CASH FLOWS for the Year Ended 31 December 2018

1.	RECONCILIATION OF NET INCOME TO NET CASH I	FLOW FROM	OPERATING
			as restated
		2018 £	2017 £
	Net income for the reporting period (as per the statement	~	~
	of financial activities) Adjustments for:	208,476	(66,004)
	Depreciation	49,174	46,358
	Decrease in debtors	14,880	148,486
	Increase in creditors	<u>(381,930</u>)	<u>192,241</u>
	Net cash provided by (used in) operating activities	(109,400)	321,081
2.	ANALYSIS OF CASH AND CASH EQUIVALENTS		
		2018 £	2017 £
	Cash in hand	3,530	1,478
	Bank accounts	<u>1,181,688</u>	1,715,174
	Total cash and cash equivalents	1,185,218	1,715,652

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS for the Year Ended 31 December 2018

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', the Charities and Trustee Investment (Scotland) Act 2005 and the Companies Act 2006. The financial statements have been prepared under the historical cost convention with the exception of investments which are included at market value.

The presentational currency of the financial statements is the Pound Sterling (£).

Basis of consolidation

The financial statements consolidate the accounts of Society for Mucopolysacharide Diseases and its wholly owned subsidiary MPS Commercial Limited on a line-by-line basis.

A separate Statement of Financial Activities and Income and Expenditure account has not been presented because advantage has been taken of the exemption permitted by section 408 of the Companies Act 2006.

Preparation of the accounts on a going concern basis.

The trustees have considered the future trading of the Charity and the Group and have prepared forecasts for a period of 12 months from the date these financial statements were signed. They have a reasonable expectation that the Charity and the Group can continue to meet its liabilities as they fall due. On this basis, the trustees consider it appropriate to prepare the financial statements on the going concern basis.

Critical accounting estimates and judgement

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.

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.

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

1. ACCOUNTING POLICIES - continued

Grants receivable

Grants receivable are included in the SOFA in the year in which they relate. Grants received relating to future projects are dealt with as grants received in advance and are carried forward as a creditor in the balance sheet at the year end.

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 wholly owned 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.

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.

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.

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 102.23.4).

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

1. ACCOUNTING POLICIES – continued

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.

Tangible fixed assets

Expenditure on fixed assets costing over £800 is capitalised. Expenditure on property and property improvement is depreciated on a straight-line basis over 50 years. Expenditure on computers and office furniture is depreciated on a straight-line basis over 3 years. Investment assets are included at market value. Investment assets are valued at open market value at the date of donation and subsequently revalued to open market value at least every 5 years.

Fixed asset investments

Fixed asset investments are initially measured at cost and subsequently measured at cost less any accumulated impairment losses. The investments are assessed for impairment at each reporting date and any impairment losses or reversals of impairment losses are recognised immediately in net income/(expenditure) for the year.

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.

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.

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.

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.

Pension costs and other post-retirement benefits

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

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

2. LEGAL STATUS

The charity is a company limited by guarantee. The members of the parent company charity are the trustees named on page 3. 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

3. DONATIONS AND LEGACII	ES			
			2018	2017
5			£	£
Donations			93,677	74,820
Legacies			50,800	
			144,477	<u>74,820</u>
4. INCOME FROM CHARITAB	LE ACTIVITIES			
	2018	2018	2018	2017
	Unrestricted	Restricted	Total	Total
	fund	fund	funds	funds
	£	£	£	£
Research grants	-	12,747	12,747	16,797
Support grants	9,257	248,295	257,552	316,151
Conferences	7,892	30,000	37,892	122,837
Family support special events	4,600	16,725	21,325	30,620
Overseas co-operation	441	13,500	13,941	8,439
Childhood wood	50	3,775	3,825	830
Magazine and resource material	1,304	25,890	27,194	26,951
Christine Lavery Memorial Fund	-	91,336	91,336	-
Fundraising events	135,230	31,012	166,242	134,161
Other income	2,824		2,824	4,917
	161,598	473,280	634,878	661,703

In 2017, of the total income from charitable activities, £357,386 was to unrestricted funds and £304,317 was to restricted funds.

5. OTHER TRADING ACTIVITIES

	2018 £	2017 £
Survey income in subsidiary	198,978	197,699
Management fees in subsidiary	486,707	349,461
	685,685	547,160

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

6.	INVESTMENT IN	COME				
	Rents received Deposit account i	nterest			2018 £ 32,270 5,343	2017 £ 45,735 5,813
					<u>37,613</u>	51,548
7.	EXPENDITURE (ON RAISIN	G FUNDS			
		Note	Fundraising Grants & Donations	Fundraising Events	Commercial Trading Activity	Total 2018
			£	£	£	£
	Staff costs		40,000	32,566	257,047	329,613
	Direct costs	9	- ,	6,958	37,907	44,865
	Support costs	10	21,628	21,628	145,139	188,395
		-	61,628	61,152	440,093	562,873

8. EXPENDITURE ON CHARITABLE ACTIVITIES

	Note	Advocacy & Members Events	Awareness Raising	Management Administration & Support	Total 2018
		£	£	£	£
Staff costs		333,203	8,141	52,473	393,817
Direct costs	9	162,727	1,740	-	164,467
Support costs	10	108,138	21,629	43,254	173,021
	-	604,068	31,510	95,727	731,305

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

Note Learning Note Expenditure 2018 Restricted expenditure 2018 Funds 2017 Total funds 2017 Total funds 2017 Total funds Total funds Total funds 2018 funds 2017 Total funds Total funds 2018 funds 2017 Total funds 2018 funds 2017 Total funds 2018 funds 2018 funds 2017 Total funds 2018 funds 2018 funds 2017 Total funds 2018 funds <th colspan="8">9. ALLOCATION OF DIRECT COSTS</th>	9. ALLOCATION OF DIRECT COSTS							
Conference and expert meetings	, , , , , , , , , , , , , , , , , , ,		2018 Unrestricted expenditure	Restricted expenditure	Total funds	Total funds		
meetings - 34,142 34,142 81,467 Support events - 17,442 17,442 23,617 Overseas co-operation - 20,241 20,241 13,209 Childhood wood - 700 700 1,096 Communications - 13,957 13,957 7,655 Research grants 11 - 20,300 20,300 145,810 MPS awareness day 29,960 - 29,960 - 29,960 - Fundraising Expenses 8,698 - 8,698 10,696 Donations and tributes in memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 Attributable to raising funds 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928			-	19,103	19,103	23,414		
Overseas co-operation - 20,241 20,241 13,209 Childhood wood - 700 700 1,096 Communications - 13,957 13,957 7,655 Research grants 11 - 20,300 20,300 145,810 MPS awareness day 29,960 - 29,960 - 29,960 - Fundraising Expenses 8,698 - 8,698 10,696 Donations and tributes in memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 Attributable to raising funds Attributable to charitable activities 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928	meetings		-					
Childhood wood - 700 700 1,096 Communications - 13,957 13,957 7,655 Research grants 11 - 20,300 20,300 145,810 MPS awareness day 29,960 - 29,960 - Fundraising Expenses 8,698 - 8,698 10,696 Donations and tributes in memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 76,565 132,767 209,332 375,489 Attributable to raising funds Attributable to charitable activities 8 31,700 132,767 164,467 296,928	• •		-	•	·	•		
Communications - 13,957 13,957 7,655 Research grants 11 - 20,300 20,300 145,810 MPS awareness day 29,960 - 29,960 - 29,960 - Fundraising Expenses 8,698 - 8,698 10,696 10,696 Donations and tributes in memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 Attributable to raising funds 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928	•		-	•	·	·		
Research grants 11 - 20,300 20,300 145,810 MPS awareness day 29,960 - 29,960 - Fundraising Expenses 8,698 - 8,698 10,696 Donations and tributes in memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 Attributable to raising funds 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928	Childhood wood		-	700	700	1,096		
MPS awareness day 29,960 - 29,960 - Fundraising Expenses 8,698 - 8,698 10,696 Donations and tributes in memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 76,565 132,767 209,332 375,489 Attributable to raising funds Attributable to charitable activities 8 31,700 132,767 164,467 296,928	Communications		-	13,957	13,957	7,655		
Fundraising Expenses 8,698 - 8,698 10,696 Donations and tributes in memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 76,565 132,767 209,332 375,489 Attributable to raising funds Attributable to charitable activities 8 31,700 132,767 164,467 296,928	Research grants	11	-	20,300	20,300	145,810		
Donations and tributes in memory memory - 2,244 2,244 535 Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 76,565 132,767 209,332 375,489 Attributable to raising funds Attributable to charitable activities 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928	MPS awareness day		29,960	-	29,960	-		
Management fee - 4,638 4,638 1,992 Survey costs 37,907 - 37,907 65,998 76,565 132,767 209,332 375,489 Attributable to raising funds Attributable to charitable activities 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928			8,698	-	8,698	10,696		
Survey costs 37,907 - 37,907 65,998 76,565 132,767 209,332 375,489 Attributable to raising funds Attributable to charitable activities 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928	memory		-	2,244	2,244	535		
76,565 132,767 209,332 375,489 Attributable to raising funds Attributable to charitable activities 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928	Management fee		-	4,638	4,638	1,992		
Attributable to raising funds 7 44,865 - 44,865 78,561 Attributable to charitable activities 8 31,700 132,767 164,467 296,928	Survey costs	•	37,907		37,907	65,998		
Attributable to charitable activities 8 31,700 132,767 164,467 296,928			76,565	132,767	209,332	375,489		
		7	44,865	-	44,865	78,561		
76,565 132,767 209,332 375,489	activities	8	31,700	132,767	164,467	296,928		
			76,565	132,767	209,332	375,489		

In 2017, of the total expenditure for direct costs, £253,071 was to unrestricted funds and £122,418 was to restricted funds. All restricted expenditure in 2017 was attributable to charitable activity expenditure.

10.	ALLOCATION OF SUPPORT COSTS				
		Note	2018		2017
			£		£
	Recruitment & training costs		13,873		13,997
	General office expenses		95,768		131,153
	Governance		6,525		18,304
	Subscriptions		3,759		2,606
	Staff entertaining		5,566		583
	Computer expenses and software		76,014		29,757
	GDPR and database implementation		6,710		-
	Professional fees		12,219		11,293
	Bank charges		3,063		4,101
	Bank interest		8,816		16,347
	Bad debts		3,263		226
	Depreciation Travel and subsistence		49,174		46,358 35,570
			39,568 32,136		35,570 6,021
	Consultancy expenses Commercial meetings		262		0,021
	Auditors remuneration		4,700		3,600
	Additional Control of the Control of		4,700		3,000
			361,416		319,916
	Attributable to raising funds	7	188,395		156,714
	Attributable to charitable activities	8	173,021		163,202
			361,416		319,916
11.	GRANTS PAYABLE				
				2018	2017
	Grants and donations			£ 20,300	£ 145,809
			=		
	Grants payable to institutions				C
	University of Manchester				£ 20,300
12.	NET INCOME/(EXPENDITURE)				
	Net income/(expenditure) is stated after ch	arging/(cre	editing):		
				2018	2017
				£	£
	Auditors' remuneration			4,700	3,600
	Depreciation			49,174	46,358
					_

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

13. TRUSTEES' REMUNERATION AND BENEFITS

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

Trustees' expenses

All trustees are reimbursed for their expenses 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 2018 these totalled £6,525 (2017:£18,304).

14. STAFF COSTS

	2018	2017
	£	£
	649,537	681,962
Social security costs	59,844	66,254
Other pension costs	<u>17,049</u>	21,182
	726,430	769,398

The key management personnel of the parent charity and subsidiary comprise the trustees, Chief Executive Officer, Head of Advocacy, Head of Fundraising, Head of Finance and the Chief Executive Officer. The total remuneration of the key management personnel for 2018 was £198,800.

One employee earned £60,000 p.a. or more (2017: 1 employee).

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

	2018 No.	2017 No.
Director	1	1
Administration	3	2
Advice, information and support services	23	22
	27	<u>25</u>

		Unrestricted	Restricted	Total
		funds £	funds £	funds £
	INCOME			
	Voluntary income:			
	Donations & legacies	74,820	-	74,820
	Activities for generating funds:			
	Charitable activities	357,386	304,317	661,703
	Other trading activities	547,160	_	547,160
	Investment income	51,548	-	51,548
	TOTAL INCOME	1,030,914	304,317	1,335,231
	EXPENDITURE			
	Raising funds:			
	Fundraising grants & donations	69,200	-	69,200
	Fundraising activities	81,686	-	81,686
	Trading activities	332,676		332,676
		483,562	-	483,562
	Charitable activities:			
	Advocacy services & member events	538,084	253,071	791,155
	Awareness raising	34,654	-	34,654
	- -	572,738	253,071	825,809
,	Other costs	91,864	-	91,864
	TOTAL EXPENDITURE	1,148,164	253,071	1,401,235
	NET INCOME / (EXPENDITURE) BEFORE TRANSFERS	(117,250)	51,246	(66,004)
	Transfers between Funds	492,845	(492,845)	
	NET INCOME / (EXPENDITURE)	375,595	(441,559)	(66,004)
	RECONCILIATION OF FUNDS			
	Total funds brought forward	1,661,773	492,845	2,154,618

_				_
16.	TANGIBLE FIXED ASSETS Group			-
		Land and buildings £	Plant and equipment £	Totals £
	COST			
	At 1 January 2018 Additions	1,435,389 ————————————————————————————————————	254,050 7,034	1,689,439 7,034
	At 31 December 2018	1,435,389	261,084	1,696,473
	DEPRECIATIONS			
	At 1 January 2018	264,744	226,864	491,608
	Charge for year	28,708	20,466	<u>49,174</u>
	At 31 December 2018	293,452	247,330	540,782
	NET BOOK VALUE			
	At 31 December 2018	<u>1,141,937</u>	13,754	<u>1,155,691</u>
	At 31 December 2017	1,170,645	27,186	1,197,831
	TANGIBLE FIXED ASSETS Charity			
	•	£	£	£
	COST	4 405 000	000 400	4 044 500
	At 1 January 2018 Additions	1,435,389 -	209,180 5,412	1,644,569 5,412
	At 31 December 2018	1,435,389	214,592	1,649,981
	DEPRECIATION	20171	100 105	155 133
	At 1 January 2018 Charge for year	264,742	190,435 13,795	455,177 42,504
	Charge for year	28,709	13,795	42,504
	At 31 December 2018	293,451	204,230	497,681
	NET BOOK VALUE			
	At 31 December 2018	<u>1,141,938</u>	10,362	1,152,300
	At 31 December 2017	1,170,647	18,745	1,189,392

	2018 Group £	2018 Charity £	2017 Group £	2017 Charity £
Shares in subsidiary Donated jewellery	- 6,100	1 6,100	- 6,100	1 6,100
	6,100	6,101	6,100	6,101
Investment in subsidiary Shares in subsidiary: MPS Commercial Company number: 08621283 Registered Office: MPS House, Repton Place Buckinghamshire, HP7 9LP Shareholding: Ordinary shares, 100% holding	ce, White Lio		_	nd Wales.
MARKET VALUE 1 ordinary share				£ 1
NET BOOK VALUE At 31 December 2017 and 31 December 20	18			1
There were no investment assets outside the	e UK.			
18. DEBTORS: AMOUNTS FALLING DUE	WITHIN ON	IE YEAR		
	2018 Group £	2018 Charity £	2017 Group £	2017 Charity £
Trade debtors	77,231	E24		
Amounts owed by group undertakings Other debtors Prepayments	- 81,281 19,279	531 459,750 81,178 17,758	99,683 - 57,932 35,056	414,605 27,877 12,746
Other debtors	·	459,750 81,178	57,932	27,877
Other debtors	19,279	459,750 81,178 17,758	57,932 35,056	27,877 12,746
Other debtors Prepayments	19,279 177,791 2018 Group	459,750 81,178 17,758 559,217 2018 Charity	57,932 35,056 192,671 2017 Group	27,877 12,746 455,228 2017 Charity

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

20.	CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR				
		2018 Group £	2018 Charity £	2017 Group £	2017 Charity £
	Trade creditors Other creditors Accrued expenses Bank loans and overdrafts (see note 22)	13,136 38,589 175,985 	7,969 2,742 8,051 	22,999 572,375 14,266 135,000 744,640	1,877 56,067 3,900 135,000 196,844
21.	CREDITORS: AMOUNTS FALLING AF				
		2018 Group £	2018 Charity £	2017 Group £	2017 Charity £
	Bank loans and overdrafts (see note 22)	-	<u>-</u>	280,000	280,000

22. SECURED DEBTS

At 31 December 2017 the charity had loans outstanding with Barclays Bank PLC. These loans were fully repaid in the year ended 31 December 2018.

	2018	2018	2017	2017
	Group	Charity	Group	Charity
	£	£	£	£
Bank loans	_	•	415,000	415,000

Barclays Bank PLC no longer has any legal charges over the properties Nash House and MPS House.

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

23.	ANALYSIS C	F NET AS	SETS BET	WEEN FUNDS
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24.

Total Funds

ANALISIS OF NET	ASSETS BE	I WEEN FOND	•		
Fixed assets Investments Current assets Current liabilities Long term liabilities		Unrestricte fund £ 1,155,69 6,10 1,287,58 (227,71	s funds £ 1 - 0 - 9 75,420	2018 Total funds £ 1,155,691 6,100 1,363,009 (227,710)	2017 Total funds £ 1,197,831 6,100 1,909,323 (744,640) (280,000)
		2,221,67	0 75,420	2,297,090	2,088,614
MOVEMENT IN FUN	NDS				
	Funds as at 1 January 2018	Income	Expenditure	Fund Transfers	Funds as at 31 December 2018
Unrestricted					
General charitable fund	866,723	1,029,373	(810,366)	(305,996)	779,734
Property fund	1,170,645		(28,709)		1,141,936
Total unrestricted funds	2,037,368	1,029,373	(839,075)	(305,996)	1,921,670
Designated Research fund	-	-	-	100,000	100,000
Service development fund	•	-	-	100,000	100,000
Building refurbishment fund	-	-	-	100,000	100,000
Total designated funds	<u> </u>	-	-	300,000	300,000
Restricted MPS restricted fund LSD restricted fund CL Memorial fund	51,246 - -	369.197 12,747 91,336	(363,766) - (91,336)	- 5,996 -	56,667 18,743
Total restricted funds	51,246	473,280	(455,102)	5,996	75,420
		4.500.050			

<u>2,088,614</u> <u>1,502,653</u> <u>(1,294,</u>177)

2,297,090

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2018

25. RELATED PARTY DISCLOSURES

MPS Commercial Limited is a 100% owned subsidiary of The Society for Mucopolysaccharide Diseases.

Included in other debtors within the Charity are the profits of MPS Commercial Limited for the period which have been distributed by gift to the Charity. The profits for the year total £231,788 (2017: £214,605).

26. ULTIMATE CONTROLLING PARTY

The charity is controlled by the trustees.

27. FUNDS HELD AS INTERMEDIARY AGENT

As at 31 December 2017, the charity held funds on behalf of newly formed company Medics 4 Rare Diseases Ltd and in accordance with the SORP, they were not included on the balance sheet. No such funds were held at 31 December 2018 (2017: £36,025).

28. PRIOR PERIOD ADJUSTMENT

In previous years the accounts of the subsidiary MPS Commercial Limited have shown monies coming in and being reimbursed as gross income and expenditure. As these technically represent pass through costs they have been eliminated from the current and prior year figures. The profit is unaffected.