

MDS UK PATIENT SUPPORT GROUP

(A charitable company limited by guarantee)

Unaudited Financial Statements

Year ended 31st March 2018

Registered Company Number: 07818480

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

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Registered Company Number: 07818480

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2018

The Directors, who are also trustees, submit their report together with the financial Statements for the year ended 31st March 2018.

Results

The results for the year and the financial position of the company ("MDSUK") are shown in the annexed financial statements. The company is a non-profit distributing company limited by guarantee and is a registered charity (No, 1145214).

The financial statements have been prepared in accordance with the accounting policies and comply with the Charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard (FRS 102). The Charity has taken advantage of the exemption in Financial Reporting Standards from producing a cash flow statement on the grounds that it is entitled to the exemption for smaller companies available in Section 38 of the Companies Act 2006.

Chair's Report

The past year has been one of change, with the Charity seeking to extend its ability to help those suffering from MDS. Some of the existing members of the Management Board stepped down and the Charity are still in the process of seeking new members with the necessary skills to help in the development of the Charity. The way in which the Board is established, with the majority of members being those suffering from MDS, means that this process is not easy as many willing people are unable to contribute due to their illness. In time, it is hoped to fill all those specific roles within the Board that were previously identified.

The Head of Fundraising is currently researching a Fundraising Strategy which, when devised and adopted, will enable us to call on a wider variety of funding sources to support our aims and objectives. In a similar way, the Board have taken the decision to fund research for the first time, in addition to our on-going involvement in several areas of research. To enable this to be done in a structured and financially viable manner, a Research Strategy is in the process of being formulated with the assistance of haematology clinicians.

A legal Constitution has been written by the current Chair and approved by the Trustees and Management Board. Our aims and objectives have been amended and updated in the Constitution to reflect the decisions made by the Trustees and Management Board. In addition, the new Code of Conduct has been incorporated into the Constitution so that the document can be utilised as a standard reference document for the Charity. It is intended to take advantage of the opportunity to change the structure of the Charity to a Charitable Incorporated Organisation (CIO) in 2018. As soon as that takes place, the new Constitution will be formally adopted.

Caitlin Limmer has been appointed a new Patron for the Charity in recognition of her long-standing work in fundraising for MDS. She is a tireless worker and her help in spreading knowledge and understanding of MDS is greatly appreciated. MDS UK is continually grateful for

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Report of the Directors for the year ended 31st March, 2018

the support, enthusiasm and dedication it receives from all its donors, including the many private individuals, in addition to the pharmaceutical companies Celgene, Novartis Oncology and Janssen. Without the support of all those people and organisations, MDS UK would be unable to continue in its support of those suffering from MDS.

I would finally like to thank the Trustees and Members of the Management Board, who freely give their time and energy, and the Chief Executive Officer and her staff for their work and dedication



Edward Peel
Chair

Our purposes and activities

The Charity's principal activities during the year under review relate to the support of individuals suffering Myelodysplastic Syndrome ("MDS"), which is a rare blood cancer. The activities were previously carried on by a trust with the same name and were taken over by the company with effect from 1st April 2012.

The objects of the Charity are:

- (i) To relieve the sickness and preserve, promote and protect the health of sufferers of MDS in the United Kingdom through the provision of support, education and practical advice.
- (ii) To advance the education of the general public in the United Kingdom in all areas in relation to MDS.
- (iii) To promote and support scientific research into MDS and its treatment together with the care of MDS sufferers and those disposed to the development of MDS.

Achievements and performance

The Charity's main activities are the operation and maintenance of a website, the telephone helpline and e-mail support, regional and national group meetings as well as the Facebook page. MDS (UK) has continued to increase its advocacy work at both UK and European levels where it affects UK issues. All of these activities provide support and information to MDS sufferers and their families.

Achievements this year included: -

- The MDS UK Patient Survey has completed recruitment and achieved the largest

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Scientifically representative sample of MDS patients in the UK and data is being analysed. Preliminary data has been published within MDS UK platforms – with outside publications being worked on.

- MDS UK promoted the fifth 'MDS World Awareness Day' in conjunction with international colleagues and the MDS Alliance. This event will continue to be marked in the future.
- The charity conducted 3 national patient forum events this year, as opposed to a single national event in London.
- The charity revised their membership procedure in light of the GDPR changes.
- The Charity has promoted its services and activities at multiple educational events throughout the UK, to groups of patients, nurses, physicians and pharma industry, through presentations and information stands.
- The MDS Patient Handbook (in collaboration with Leukaemia CARE and Bloodwise) has started the 2nd Revision process.
- MDS UK continued to be actively involved at European and international level through organisations such as EMA (European Medicines Agency) ESH (European School of Haematology), EHA (European Haematology Association) and ASH (American Society of Haematology), together with other MDS overseas groups. Alliance activities have again increased, with MDS UK being a founder member and one of the core members due to experience and success in the UK. The formal co-operation will be of particular importance with regard to EMA licensing of new drugs.
- MDS UK, via the MDS Alliance, has continued to work on the new European project on rare diseases called ERN's (European Reference Networks). The ERN dedicated to rare haematology conditions is called EuroBloodNet and the main purpose is to share best practice across Europe as well as facilitate cross-border healthcare and a wider access to clinical trials.

Also via MDS Alliance, MDS UK has become an active contributor to the scientific public-private partnership project, HARMONY, which represents a unique data-sharing collaboration across European research centres which aims to provide answers to specific unresolved research queries.

These European activities were presented by MDS UK at an oral session at the British Society of Haematology national congress, for the benefit of the UK based haematologist audience.

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- The specific Clinical Trial information service continues to be popular and accessed by patients, but also haematologists, and the Principal Investigators who can struggle to recruit rare sub-types of patients.
- In terms of clinical trials, MDS UK has accepted to be co-applicants in two university hospital led trials, providing the patient perspective at all levels of the project. A third clinical trial project for Watch&Wait patients was started – and work is on going.
- MDS UK was involved in the development of an innovative Patient Reported Outcome tool to capture real-time data of patients. This tool has now been presented at major haematology congresses.
- MDS UK presented data at the national expert's UK MDS Forum – in collaboration with expert MDS nurses.
- MD SUK started work on a further innovative digital project – in cooperation with company developing a new tool capturing Quality of Life information.

Financial Review

Total income for the year of £204,145 was 83% higher than the previous year (2016/17 - £111,689) as a result of a generous legacy of £74,867 received in the year. Donations of £89,435 were 26% higher compared to last year whilst grants remained at the same level as last year. Grants were received from the pharmaceutical companies, Celgene and Janssen. The grants are unrestricted and comply with the Code of Practice for the UK Pharmaceutical Industry.

Total expenditure for the year of £143,997 was £70,078 more than last year. This was largely due to appointment of a full time project worker seconded from Kings College London, development of our donor database, publication of the newsletter and issue of Patient Handbooks

The surplus for the year of £60,148 has been added to unrestricted reserves that now amount to £375,891. The receipt of the legacy and their confidence in the level of reserves has enabled the Directors to pursue the third objective of the Charity, 'to promote and support scientific research into MDS and its treatment'. The Board has designated £100,000 of the reserves to support this objective in 2018/19.

Reserves Policy and going concern

Reserves are needed to bridge the gap between the spending and receiving of income and to support the activities of the Charity in the event of a significant reduction in income. From time to time the directors review the required level of reserves. As referred to above, £100,000 of the reserves has been designated to support scientific research into MDS and its treatment. The remaining reserves are considered adequate to maintain the activities of the Charity.

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Report of the Directors for the year ended 31st March, 2018

The directors are not aware of any material uncertainties relating to events or conditions that may cast significant doubt about the ability of the Charity to continue as a going concern and have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future.

Reference and administrative details

Charity number: 1145214
Company number: 07818480
Registered Office: Haematology - Bessemer Wing (Ground Floor), Kings
College Hospital, Denmark Hill, London SE5 9RS.

Our Advisors

Examiner: David King, FCA The Dell, Old Farm Rd, Hampton, TW12 3RJ
Bankers: CAF Bank Ltd
Co-Operative Bank Ltd
CCLA Investment Management Ltd
Scottish Widows Bank Ltd
Nationwide Building Society
Hampshire Trust Bank

Directors and trustees

The directors of the charitable company (the charity) are its trustees for the purpose of charity law. The trustees serving during the year and since the year end were as follows:

Edward Peel
Sophie Wintrich
Fiona Pirilla
John Taylor (until May 2018)
Don Barrett
Russell Cook
Chris Charlwood
Claudia Richards

Key management personnel:

Chief Executive: Sophie Wintrich

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Report of the Directors for the year ended 31st March, 2018

Structure, Governance and Management

Governing document

The entity is governed by its Memorandum and Articles of Association dated 21st October 2011. The charity is a company limited by guarantee. The members of the company who are directors are listed above. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £10 per member of the charity

Appointment of Directors

Existing directors propose new directors. The number of directors shall not be less than three and is not subject to any maximum.

Organisation

The board of directors administers the charity and normally meets quarterly. There is also a management committee which meets quarterly. A Chief Executive is appointed by the directors to manage the operations of the charity. To facilitate effective operations, the Chief Executive has delegated authority, within terms of delegation approved by the directors, for operational matters including finance and employment.

Risk Management

The directors have assessed the risks to which the charity is exposed and are satisfied that systems and procedures are in place to mitigate, where possible, those risks identified.

The principal risk is that the level of activities undertaken by the charity is dependent on the level of funding received.

Directors' responsibilities in relation to the financial statements

The directors (who are also trustees for the purposes of charity law) are responsible for preparing the Directors' Report and the financial statements in accordance with applicable law and regulations.

Company law requires the directors to prepare the financial statements for each financial year. The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard (FRS 102) for Smaller Entities.

Under company law the directors must not approve the financial statements unless they give a true and fair view of the state of affairs of the company and of the incoming resources and outgoing resources of the company for that period

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Report of the Directors for the year ended 31st March, 2018

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

(i) select suitable accounting policies and then apply them consistently;

(ii) observe the methods and principles in the Charities Statement of Recommended Practice (SORP);

(iii) make judgments and accounting estimates that are reasonable and prudent;

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

The directors are responsible for keeping proper accounting records that are sufficient to show and explain the company's transactions and disclose with reasonable accuracy at any time the financial position of the company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. The directors are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website.

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

By Order of the board of directors



Edward Peel (Chair)

Date

MDS UK PATIENT SUPPORT GROUP

Unaudited Statement of Financial Activities (Incorporating Income and Expenditure Account) for the year ended 31st March, 2018.

		2018 £	2017 £
Income from	Note	Total	Total
Donations and similar incoming resources	4	89,435	71,099
Legacies	4	74,867	-
Grants	5	39,500	39,500
Investment income	6	343	1,090
Total income		204,145	111,689
Expenditure on			
Raising Funds	7	8,092	2,341
Charitable activities	8	134,442	71,279
Other	11	1463	299
Total expenditure		143,997	73,919
Net income		60,148	37,770
Reconciliation of funds			
Total funds brought forward		315,743	277,973
Total funds carried forward		375,891	315,743

All amounts relate to continuing activities

The notes on pages 11 to 13 form part of these financial statements

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Unaudited Balance sheet As at 31st March 2018.

		2018 £	2017 £
	Note	Total	Total
Current assets:			
Debtors	13	1,992	2,534
Current asset investments	14	312,044	226,702
Cash at bank and in hand		75,414	88,003
Liabilities: Amounts falling due within one year			
Creditors and accruals	15	-13,559	-1,496
Total Net Assets		<u>375,891</u>	<u>315,743</u>
The Funds of the Charity			
Unrestricted income funds		<u>375,891</u>	<u>315,743</u>
Total funds		<u>375,891</u>	<u>315,743</u>

For the year ending 31st March 2018 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies and its members have not required the company to obtain an audit of its financial statements in accordance with section 476.

The directors acknowledge their responsibilities for complying with the requirements of the Act in respect of accounting records and the preparation of financial statements. The financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements on pages 9 to 13 were approved by the board of directors on the 15th October, 2018 and authorised for issue and signed on its behalf by:



E Peel
Chair

Registered Company Number: 07818480
Registered Charity Number: 1145214

1) Accounting policies

Basis of preparation

The Charity is a company limited by guarantee and has no share capital.

The financial statements were prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities Act 2011 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 published on 16 July 2014.

Adoption of FRS 102 has not required any changes to the accounting policies and has not affected the reported financial position or financial performance.

Fund accounting

All funds are unrestricted and are available for use at the discretion of the directors in furtherance of the general objectives of the Charity. The Board has designated a proportion of the fund to support research related to MDS.

Incoming resources

Income represents income attributable to the activities of the Charity when the Charity becomes entitled to the donation or similar income and any conditions for receipt are met, and the directors are reasonably certain that they will receive it and the value can be reliably measured.

Resources expended

Liabilities are recognised as soon as there is a legal or constructive obligation committing the Charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Irrecoverable VAT is reported as part of the expenditure to which it relates.

Charitable activities

Costs of charitable activities includes expenditure incurred in the delivery of activities and services for beneficiaries and all the support costs as shown in note 9.

Governance costs

Governance costs comprise all costs involving public accountability of the Charity and its compliance with regulation and good practice. These costs include legal and professional fees and the costs of the AGM and governance meetings

Corporation Tax

The Charity is considered to meet the definition of a charitable company for UK Corporation Tax purposes. Accordingly, the Charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 as any surplus or gains are applied for charitable purposes.

Cash flow Statement

Due to its size, the charity is not required to present a Cash flow Statement under the Financial Reporting standards.

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Unaudited notes to the financial statements as at 31st March 2018

2) Directors Remuneration

The charity reimbursed Kings College Hospital Trust for emoluments of £34,913 and pension and NI contributions of £8,712 in respect of Sophie Wintrich, the Chief Executive
The other directors neither received or waived any emoluments.

3) Directors Expenses

The charity meets the expenses incurred by directors in carrying out their duties. During the year four directors had expenses met by the charity totaling £1,409 in respect of travel and subsistence.
These are included in note 7.

4) Donations, legacies and similar incoming resources.

	2018 £	2017 £
Donations (including Gift Aid)	89,435	71,099
Legacies	74,867	-
	<u>164,302</u>	<u>71,099</u>

5) Grants

Celgene Limited	34,000	34,500
Janssen	5,500	5,000
	<u>39,500</u>	<u>39,500</u>

6) Investment Income

Bank Interest Received	<u>343</u>	<u>1,090</u>
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7) Costs of raising funds

Advertising and promotion	4,563	2,341
Event Costs	3,529	-
	<u>8,092</u>	<u>2,341</u>

8) Costs of activities for charitable objectives

Reimbursed staff costs	65,249	39,971
Donor database development/maintenance	15,680	-
Website	7,940	11,220
Newsletter	7,945	300
Literature and Information Sheets	11,831	5,658
National Forums	4,438	4,058
Local Support Groups	1,123	865
Survey	1,502	629
Conference Participation	5,323	5,020
Travel and expenses	497	955
Support costs (Note 10)	12,914	2,603
	<u>134,442</u>	<u>71,279</u>

9) Staff Costs and Emoluments

The charity does not have any employees , but it paid Kings College Hospital Trust for the services of the Chief Executive and Kings College London for the Project worker.

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Unaudited notes to the financial statements as at 31st March 2018

	2017 £	2017 £
10) Support Costs		
Contract staff	7552	-
Stationery and postage	1542	351
Telephone and broadband	1,832	1,193
Office computer and software	1548	848
Sundry expenses	440	211
	<u>12,914</u>	<u>2,603</u>
11) Other costs		
AGM & governance meetings	1300	286
Legal Fees	163	13
	<u>1463</u>	<u>299</u>
12) Taxation		
The company is a registered charity with no liability to tax arising in the year.		
13) Debtors		
Gift Aid Recoverable	1,708	2,534
Prepayments	284	-
	<u>1,992</u>	<u>2,534</u>
14) Current asset investments		
Nationwide Building Society Deposit	75,719	75,644
CCLA Charities Deposit	75,658	75,479
Co-Op Instant Access	64	64
Hampshire Trust	85,000	-
Scottish Widows Deposit	75,603	75,515
	<u>312,044</u>	<u>226,702</u>
15) Creditors		
Accruals	<u>13,559</u>	<u>1,496</u>

MDS UK PATIENT SUPPORT GROUP

INDEPENDENT EXAMINERS REPORT

I report on the accounts of MDS UK PATIENT SUPPORT GROUP for the year ended 31 March 2018, which are set out on pages 5 to 9. Your attention is drawn to the fact that the charity has prepared the accounts (financial statements) in accordance with 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) in preference to the Accounting and Reporting by Charities Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulation that has been withdrawn.

I understand that this has been done in order to provide a true and fair view in accordance with the Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

Respective responsibilities of directors and examiner

The directors are responsible for the preparation of the accounts. The directors consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- Examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145 (5) (b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a "true and fair view" and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

- 1) which gives me reasonable cause to believe that in any material respect the requirements:
 - a) to keep accounting records in accordance with section 386 of the Companies Act 2006;
 - b) to prepare accounts which accord with the accounting records, comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice: Accounting and reporting by Charities

have not been met: or

- 2) to which in my opinion attention should be drawn in order to enable a proper understanding of the accounts to be reached.

David King FCA.
Chartered Accountant
The Dell
Old Farm Rd
Hampton, TW12 3RJ

Date