

MDS UK PATIENT SUPPORT GROUP

(A charitable company limited by guarantee)

Unaudited Financial Statements

Year ended 31st March 2019

Registered Company Number: 07818480

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

Index

Page Number	Description
3 to 10	Report of the Directors
11	Unaudited Statement of Financial Activities
12	Unaudited Balance Sheet
13 to 15	Unaudited Notes to the Financial Statements

Registered Company Number: 07818480

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2019

The Directors, who are also trustees, submit their report together with the financial Statements for the year ended 31st March 2019.

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 seen us gradually progressing decisions previously taken by the Charity. I believe a broad based, dynamic fundraising strategy is essential to the growth and achievements of any charity. To that end we have embarked on a Fundraising Strategy with an established fundraising specialist company. The Strategy is broken into several phases, with the initial phases aimed at identifying similar charities to our own and analysing their fundraising activities together with a breakdown and comparison of our own income streams and expenditure over a given period. In addition, we have inserted a requirement for the contracted company to assist us in identifying a professional fundraiser in order to drive the Strategy.

A decision to enter the field of Clinical Research is also nearing fruition. A PhD project in MDS research has been advertised via the appropriate channels and we have had several applicants. We are now in the process of identifying the most appropriate subject matter and applicant. It is hoped to commission the research by the start of the new academic year.

Work has taken place to complete our transition to a Charitable Incorporated Organisation but, due to some administrative issues, it has not yet taken place. We are therefore continuing in our current form but intend to change status as soon as we are able.

Once again MDS UK has been recognised nationally and internationally for its innovative work and considerable knowledge base in addition to its successful work in supporting MDS patients. Our long-term work on patient surveys has been accepted as the most comprehensive undertaken and the results exhibited at three major haematological conferences. Much of the credit for this work rests with our Chief Executive Officer and her team who have worked tirelessly on the completion of this project. The information provided by patients is proving extremely useful to clinicians in understanding the complexities and vagaries of the impact of the disease.

MDS UK is continuing its programme of identifying suitable areas in which to seek to establish

MDS UK PATIENT SUPPORT GROUP
Report of the Directors for the year ended 31st March, 2019

Support Groups. This is not an easy task as, in addition to a supportive infrastructure, it is necessary to have the support of local specialist clinicians and those within the MDS 'family' who are willing to give of their time and energy to organise regular meetings. In the past year Support Groups have been established in Exeter and Harrogate and work is progressing on the formation of a Kent Group. In addition MDS UK has continued to assist the Support Group in Dublin. In total there are now twelve Support Groups established under our auspices.

I want to thank all those involved as volunteers with MDS UK, as they provide the vital structure of the organisation. My grateful thanks also goes to those clinicians who give of their time to assist us with our local Support Groups and the specialist nurses who are seemingly always available for helpful advice to patients in times of need. Finally, my thanks to the pharmaceutical companies who assist us with finance and those wonderful people who work to fundraise for MDS UK Patient Support Group.

Edward Peel LL.B (Hons)
Chair MDS UK



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 provision of the following services for individuals affected by MDS in the UK and Ireland:

- Maintaining a website with information about all aspects of MDS
- Running a telephone helpline and e-mail support
- Setting up and running regional and national group meetings at regular intervals
- Maintaining networking platforms for patients/relatives (Facebook and a chat forum)

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2019

- Maintaining other social media platforms (Twitter and Instagram)

In addition, MDS UK takes part in other related activities, to better serve and assist those affected by MDS:

- HTA – Health Technology Appraisals with NICE, SMC – to enable access to treatment
- Participation in clinical conferences, to raise awareness of MDS and support services to haematologists and clinical staff
- Participation in blood cancer events, to raise awareness amongst the general public

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:

- MDS UK Patient Survey – initial data was accepted as a scientific poster by the main haematology conferences in UK (BSH), Europe (EHA) and world-wide (ASH in USA). This survey is the largest scientifically representative sample of MDS patients in the UK and a proportion of data was analysed and presented. More data remains to be analysed.
- MDS World Awareness Day was marked by a very successful radio campaign, with several local and national radio stations involved around the UK.
The MDS World Awareness Day will continue to be marked in the future.
- MDS UK took part in the Make Blood Cancer Visible Campaign, to mark Blood Cancer Awareness Month in September.
- The charity conducted just 1 national patient forum event this year, due to staff shortages, but was able to create 2 new local patient groups in new locations.
- 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 2nd edition of the MDS Patient Handbook (in collaboration with Leukaemia CARE and Bloodwise) was completed and is in distribution all over the UK.
- The extended version of the MDS UK Newsletter will be maintained, due to positive feedback.
- During this year, MDS UK started to devise its research strategy, and plan to fund a PhD project for aspects of MDS.

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2019

- In terms of clinical trials, MDS UK is working with a new university hospital led feasibility trial, providing the patient perspective at all levels of the project.
- 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.
- MDS UK continues to be members of various groups and umbrella organisations, including: BCA (Blood Cancer Alliance), Cancer 52, which aim to raise awareness of blood cancer issues and rare cancers respectively.
- 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. MDS Alliance activities have been maintained, with MDS UK being chair of the group for 2 years.
- MDS UK, via the MDS Alliance, has continued to work on the 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 maintained its active contribution 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.
- In terms of staff, MDS UK revised the office set-up, by creating an Office Manager position, as well as an Administrative Support role, due to an increased level of activities and membership level.
- Significant revisions to the IT and database setup were implemented, to improve work processes.
- A Fundraising Strategy has started to be developed, to ensure longer term sustainability of the charity and its services.

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2019

Financial Review

The following figures were taken from the full accounts approved on 27th September, 2019 which have been examined by an independent examiner. This part of the trustee's annual report comments on the key features of these accounts. In this section we explain how we raised the money and then how we spent it.

Money received - £156,179. Money spent - £151,284

Overall, we ended with a surplus of £4,895 compared to a surplus of £60,148 in 2017/18.

Money received: sources of funds

Total income for the year of £156,179 was 24% lower than the previous year (2017/18- £204,145) Donations of £88,210 from members of the public and relatives of patients were similar to last year, income from legacies was lower and grants were £33,000 lower. 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

Money spent:

Total expenditure for the year of £151,284 was £7,287 more than last year. This was largely due to the publication of an additional newsletter, increased staff costs and additional contractor support costs. These increases were partly offset by lower expenditure on the development and maintenance of the donor database, lower expenditure on the website and information publications.

The surplus for the year of £4895 has been added to unrestricted reserves that now amount to £380,786. 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 £200,000 of the reserves to fund a 4 year PhD project for aspects of MDS starting in 2019/20.

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, £200,000 of the reserves has been designated to support scientific research into MDS and its treatm

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2019

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
Hampshire Trust Bank
Scottish Widows Bank Ltd
Nationwide Building Society

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 (resigned 27th May, 2018)
Don Barrett
Russell Cook
Chris Charlwood
Claudia Richards

Key management personnel:

Chief Executive: Sophie Wintrich

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2019

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

MDS UK PATIENT SUPPORT GROUP

Report of the Directors for the year ended 31st March, 2019

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

27.09.19

Unaudited Statement of Financial Activities (Incorporating Income and Expenditure Account) for the year ended 31st March, 2019.

		2019	2018
		£	£
	Note	Total	Total
Income from			
Donations and similar incoming resources	3	88,210	89,435
Legacies	3	59,797	74,867
Grants	4	6,560	39,500
Investment income	5	1,612	343
Total income		<u>156,179</u>	<u>204,145</u>
Expenditure on			
Raising Funds	6	6,771	8,092
Charitable activities	7	141,711	134,442
Other	10	2802	1463
Total expenditure		<u>151,284</u>	<u>143,997</u>
Net income		4,895	60,148
Reconciliation of funds			
Total funds brought forward		375,891	315,743
Total funds carried forward		<u><u>380,786</u></u>	<u><u>375,891</u></u>

All amounts relate to continuing activities

The notes on pages 13 to 15 form part of these financial statements

Unaudited Balance sheet
As at 31st March 2019.

		2019 £	2018 £
	Note	Total	Total
Current assets:			
Debtors	12	10,899	1,992
Current asset investments	13	320,657	312,044
Cash at bank and in hand		55,017	75,414
Liabilities: Amounts falling due within one year			
Creditors and accruals	14	5,787	13,559
Total Net Assets		<u>380,786</u>	<u>375,891</u>
The Funds of the Charity			
Unrestricted income funds		<u>380,786</u>	<u>375,891</u>
Total funds		<u>380,786</u>	<u>375,891</u>

For the year ending 31st March 2019 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 11 to 15 were approved by the board of directors on the 27th September, 2019 and authorised for issue and signed on its behalf by:

E Peel
Chair



Registered Company Number: 07818480
Registered Charity Number: 1145214

Unaudited notes to the financial statements as at 31st March 2019

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.

Unaudited notes to the financial statements as at 31st March 2019

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.

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 £6,619 in respect of conference participation, travel and subsistence. These are included in note 7.

3) Donations, legacies and similar incoming resources.

	2019 £	2018 £
Donations (including Gift Aid)	88,210	89,435
Legacies	59,797	74,867
	<u>148,007</u>	<u>164,302</u>

4) Grants

Celgene Limited	560	34,000
Janssen	6,000	5,500
	<u>6,560</u>	<u>39,500</u>

5) Investment Income

Bank Interest Received	<u>1,612</u>	<u>343</u>
------------------------	--------------	------------

6) Costs of raising funds

Advertising and promotion	2,405	4,563
Event Costs	4,366	3,529
	<u>6,771</u>	<u>8,092</u>

7) Costs of activities for charitable objectives

Reimbursed staff costs	73,386	65,249
Donor database development/maintenance	3,370	15,680
Website	5,964	7,940
Newsletters	21,343	7,945
Literature and Information Sheets	8,020	11,831
National Forums	2,689	4,438
Local Support Groups	2,711	1,123
Survey	57	1,502
Conference Participation	4,343	5,323
Travel and expenses	361	497
Support costs (Note 9)	19,467	12,914
	<u>141,711</u>	<u>134,442</u>

8) Staff Costs and Emoluments

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

Unaudited notes to the financial statements as at 31st March 2019

	2019 £	2018 £
9) Support Costs		
Contract staff	13030	7,552
Stationery and postage	397	1,542
Telephone and broadband	1,634	1,832
Office computer and software	3,520	1,548
Recruitment	770	-
Sundry expenses	116	440
	<u>19,467</u>	<u>12,914</u>
10) Other costs		
AGM & governance meetings	1,122	1,300
Legal Fees	1,680	163
	<u>2,802</u>	<u>1,463</u>
11) Taxation		
The company is a registered charity with no liability to tax arising in the year.		
12) Debtors		
Gift Aid Recoverable	1,721	1,708
Prepayments	9,178	284
	<u>10,899</u>	<u>1,992</u>
13) Current asset investments		
Nationwide Building Society Deposit	75,795	75,719
CCLA Charities Deposit	83,021	75,658
Co-Op Instant Access	64	64
Hampshire Trust	86,016	85,000
Scottish Widows Deposit	75,761	75,603
	<u>320,657</u>	<u>312,044</u>
14) Creditors		
Accruals	<u>5,787</u>	<u>13,559</u>
15) Funds		
Unrestricted funds; during the year a further £100,000 was designated to support the award of a grant to a project in 2019 to further research into the causes and treatment of MDS.		
Designated	200,000	100,000
Undesignated	180,786	275,891
	<u>380,786</u>	<u>375,891</u>

Independent examiner's report to the trustees of MDS UK Patient Support Group ('the company')

I report to the charity's trustees on my examination of the accounts of the Company for the year ended 31 March 2019.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

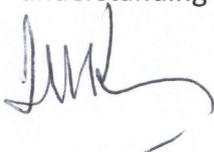
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities preparing their accounts in accordance with the Financial Reporting Standards applicable in the UK and the Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



David King
Chartered Accountant
The Dell,
Old Farm Road
Hampton, Middlesex, TW12 3RJ