

MDS UK PATIENT SUPPORT GROUP

Unaudited Financial Statements

Year ended 31st March 2023

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2023

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Registered Charity Number: 1145214

Report of the Trustees for the year ended 31st March 2023

The trustees submit their report together with the financial statements for the year ending 31st March 2023.

Results

The results for the year and the financial position of the charity ("MDSUK") are shown in the annexed financial statements. The charity is a non-profit Charitable Incorporated Organisation 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).

Chair's report

During the year under review, we began to see the light at the end of the COVID tunnel, and the World Health Organisation has since duly declared the end of the global health emergency. However, as we emerged from the lockdowns and restrictions imposed during the last three years, it became clear that things will not quickly return to 'normal' and we are all aware of the difficulties the health service currently has in provision of care and support for patients. During last year it was important that communications with and between our members on developments generally, and with specific reference to the needs of MDS and CMML patients, continued. I am pleased to say that feedback on the quality and effectiveness of our support continues to be at a high level.

However, it became clear during the last year that the relentless pressure on our staff and volunteers to provide the necessary support to members was affecting their well-being. As a result, we employed additional resource to support our administration and have reviewed our communications and back office support, in order to improve efficiency and effectiveness. During the year we also reviewed our strategic objectives and are putting in place our plans to achieve the planned extensions and improvements in patient support and our work in aiding research into MDS and CMML. These plans require investment in people and systems and we are fortunate that our fund-raising remained robust during the last year, allowing us to implement the changes we have already agreed. We are confident that we can continue to provide and extend the support that our members need as they deal with the consequences of the diagnosis they have received.

Sadly, as I write, Sophie Wintrich has had to take extended leave, and has decided to step down as CEO; we all wish her a speedy recovery. We are grateful to Debbie Hickman, who had been employed as Deputy CEO for part of the year, for agreeing to take on the full role during this important time.

I would also like to thank all our staff for the work they continue to do, and all others who have worked hard in supporting our members - patient support ambassadors, fund-raisers, other

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Report of the Trustees for the year ended 31st March 2023

supporters and our trustees.

We are fortunate to have attracted two new trustees who were appointed during the year and one new trustee since the start of this year; the positive results of their involvement in the management of our charity is already very evident. I would like to thank the three trustees who have stepped down as trustees at the time of this report – Don Barrett, Chris Charlewood, who have retired, and Sophie Wintrich, whose role as CEO had made it difficult to maintain her position as a trustee. They have all freely invested their time and energy in support of our members during many years.

Finally, I send my best wishes to all our members, patients and their families and pledge that we will continue to look for improvements in all our support services, assisting them in dealing with the personal consequences of their condition.

Tony Allen
Acting Chair MDS UK
July 2023



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.

Report of the Chief Executive

Objectives and achievements

MDS UK's charitable purpose has two main strands:

- The provision of patient support, at both group and individual levels, to those suffering from the disease, as well as their families and carers;

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- To operate in and liaise with within the wider MDS community, supporting drug and clinical research by providing patient expertise, and through affiliation with other blood cancer organisations and agencies, at both national and international levels.

To fulfil these objectives, the charity's main activities continue to be:

1. Patient/user level:

- Maintaining and growing a secure database of members
- Outreach to newly diagnosed MDS/CMML patients
- Facilitating online patient support meetings (resuming F2F not yet feasible at 03/23)
- Compiling, publishing and circulating a monthly online newsletter to members
- Facilitating online, subject-specific forums and Q & As, with guest speakers
- Maintaining an up-to-date, user-friendly website/social media platforms
- Facilitating a user-friendly member chat forum (hosted on website)
- Producing/updating patient information literature and membership packs
- Providing a helpline and signposting service, by telephone and email
- Providing individual patient advocacy where feasible/relevant.

2. Wider MDS community:

- Liaison/co-operation with partner/affiliate charities
- Representation of charity at national/international level
- Supporting/promoting clinical research
- providing PPI for clinical trials
- participation in national and international conferences and forums.

Main achievements in this financial year include:

- Worked with Warwick University to successfully launch REPAIR-MDS trial, encouraging member participation
- Maintained support to an increasing member/user base; improved database security
- Established links with charity AbilityNet, to enable more members to participate online
- Increased number of speaker-led presentations; increased member participation
- Reviewed IT and administrative processes, to streamline operational functions and improve efficiency
- Reviewed internal policies and procedures to ensure full compliance

Report of the Trustees for the year ended 31st March 2023

- Jointly participated in national and international initiatives including Blood Cancer Awareness Month, MDS World Awareness Day.
- Supported campaigns for drug availability (inc Luspatercept, Evusheld)
- Partnered with Leukaemia Care to develop and promote 'Malignant Diagnosis, Surely?' Campaign

Operations

The charity conducts a full review of systems and processes each year, and sets aims and objectives for the coming period. We had managed to fulfil its main objectives, continuing to provide support to patients and full participation in clinical work through the pandemic in the previous two years. We have continued to review whether face-to-face support can be resumed at the same time as improving and expanding its online services. By engaging with AbilityNet, we can now offer direct IT support to members, enabling as many as possible to participate in online forums, meetings, webinars etc.

An Operations Manager was appointed in July 2022 on an initial six-month contract, with a remit to review systems, policies and processes, as well as manage all day-to-day internal operations. Initially a part-time appointment, hours were increased in October 2022, enabling the long-serving CEO to take extended leave during a period of illness and family bereavement. In addition, an experienced Business Analyst was appointed on a six-month contract to review IT systems, and considerable improvements have now been made to the charity's operational systems and data security. New policies were introduced and existing policies updated and improved. Further policy requirements have been identified and will be introduced during the next 12 months.

2023/24 strategic objectives

Following the appointment of a new Treasurer in early 2023, a full review of financial processes and banking arrangements will take place shortly in 2023/24.

A move to new office premises were put on hold during this period, this is now planned for 2023/4.

Other priorities for 2023/4 include:

- Full review of, and capital investment into, existing website
- Review of all patient information literature
- Review and improvements to helpline function and systems
- Feasibility review of current database with a view to improving efficiency and security; possible migration to CRM
- Further improvements to internal processes and working practices
- Full review of all HR documents and contracts
- Optimise staffing structure to meet strategic objectives

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Report of the Trustees for the year ended 31st March 2023

- Review and agree fundraising/legacy strategy moving forward.

Debbie Hickman, Interim CEO
June 2023

Financial review

The following figures were taken from the full accounts approved on XXXXXXX. 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 - £402,047. Money spent - £204,117.

Two legacies contributed to a surplus of £196,630 compared to surplus of £416,327 in 2021/22.

Money received: sources of funds

We received donations of £119,364 from members of the public and relatives of patients. This was an increase of 15% compared to last year.

We were fortunate to receive two legacies during the year amounting to £260,000 (2021/22 £308,253). We are extremely grateful to those who choose to recognise the work of the charity in this way.

As referred to in the Chair's report the research programme at Queen's University Belfast was terminated in September 2022. This has been recognised as a significant post balance sheet event and we have written back the provision for the unspent grant.

Money spent:

Expenditure for the year of £204,117 (£107,100 2021/22). This year's accounts report the costs of each of our charitable activities. The comparative figures are restated accordingly.

The surplus for the year of £196,630 has been added to unrestricted reserves which now amount to £802,894. This is outside the parameters of our policy on reserves. A strategy review was held during this year to consider the opportunities offered by the excess reserves to extend our activities but our immediate priority is the improvement of staff levels and systems to enable this to happen.

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 trustees review the required level of reserves. The trustees have reviewed the ability of the charity to raise funds and the increase in demand for our services. They have concluded that the budgeted income and expenditure with the existing level of free reserves is sufficient for

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Report of the Trustees for the year ended 31st March 2023

the Charity to be able to continue as a going concern

Reference and administrative details

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

Our Advisors

Examiner: Orchard Accountants, The Old Court House, New Road Avenue, Chatham, Kent,
ME4 6BEJ

Bankers: CAF Bank Ltd
Charity Bank
Co-Operative Bank Ltd
CCLA Investment Management Ltd
Hampshire Trust Bank
Scottish Widows Bank
Redwood Bank Ltd

Trustees

The trustees serving during the year and since the year end were as follows:

Edward Peel
Sophie Wintrich (resigned 28th April 2023)
Don Barrett (resigned 24th February 2023)
Russell Cook
Chris Charlwood (resigned 24th February 2023)
Fiona Pirilla (resigned 21st May 2021)
Claudia Richards
Tony Allen (appointed 1st October 2021)
Lin Holder (appointed 1st October 2021)
John Evason (appointed 24th February 2023)
Alastair Day (appointed 24th February 2023)

Key management personnel:

Chief Executive: Debbie Hickman (acting CEO)

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Report of the Trustees for the year ended 31st March 2023

Structure, governance and management

Governing document

The Charity changed from a company limited by guarantee to a Charitable Incorporated Organisation (CIO) governed by a constitution dated 23rd October 2020. The members of the CIO who are trustees of the charity are listed above.

Appointment of trustees

Existing trustees propose new trustees. The number of trustees shall not be less than three and a maximum of eight.

Organisation

The board of trustees administers the charity and normally meets quarterly. A Chief Executive is appointed by the trustees to manage the day to day activities to facilitate effective operations. The Chief Executive has delegated authority, within terms of delegation approved by the trustees, for operational matters including finance and employment.

Equal opportunities

The Charity operates a policy of equal opportunities. All recruitment, employment practice and service delivery within the organisation is carried out according to the principles of equal opportunities.

Risk management

The trustees 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 the ability to replace key staff and trustees and our ability to secure staff for the planned expansion of activities.

Register of interests

A register has been set up in which trustees are required to declare their outside interests, specifically directorships of other boards.

Trustee's responsibilities in relation to the financial statements

The trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and regulations. Charity law requires the trustees 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

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Report of the Trustees for the year ended 31st March 2023

charities preparing their accounts in accordance with the Financial Reporting Standard (FRS 102) for Smaller Entities.

Under charity law the trustees 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 charity for that period

In preparing these financial statements, the trustees 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 charity will continue in business.

The trustees are responsible for keeping proper accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. The trustees 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 charities.

By Order of the board of Trustees



Tony Allen (Acting Chair)

Date 1st October 2023

Unaudited notes to the financial statements as at 31st March 2023

Unaudited Statement of Financial Activities (Incorporating Income and Expenditure Account) for the year ended 31st March, 2023

		2023	2022
		£	£
	Note	Total	Total
Income from			
Donations and similar incoming resources	3	119,364	102,959
Legacies	3	260,000	308,253
Grants	4	0	1,122
Investment income	5	4,075	700
Other Income		<u>18,608</u>	<u>7,549</u>
Total income		<u>402,047</u>	<u>420,583</u>
Expenditure on			
Raising Funds	6	39,919	21,004
Charitable activities	7	164,166	86,061
Governance Costs	12	<u>32</u>	<u>35</u>
Total expenditure	8	<u>204,117</u>	<u>107,100</u>
Write back of Provision for Research grant	10	1,301	-102,844
Net income		<u>196,630</u>	<u>416,327</u>
Reconciliation of funds			
Total funds brought forward		606,264	189,937
Total funds carried forward		<u><u>802,894</u></u>	<u><u>606,264</u></u>

All amounts relate to continuing activities

The notes on pages 13 to 16 form part of these financial statements

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Unaudited notes to the financial statements as at 31st March 2023
As at 31st March 2023

		2023 £	2022 £
	Note	Total	Total
Current assets:			
Debtors	14	1,328	9,387
Current asset investments	15	377,894	372,860
Cash at bank and in hand		429,699	244,064
Liabilities: Amounts falling due within one year			
Creditors and accruals	16	6,027	-11,042
Total Net Assets		802,894	615,269
Provision for research grant	10	0	9,005
The Funds of the Charity		<u>802,894</u>	<u>606,264</u>
Unrestricted income funds	17	<u>802,894</u>	<u>606,264</u>
Total funds		<u>802,894</u>	<u>606,264</u>

The trustees are responsible for the preparation of the accounts. The trustees 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.

The trustees 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 of the Charities Act 2011 and guidance provided by the Charity Commission.

The financial statements on pages 11 to 16 were approved by the board of trustees on the 18th November, 2022 and authorised for issue and signed on its behalf by:



Tony Allen
Acting Chair

Registered Charity Number: 1145214

Unaudited notes to the financial statements as at 31st March 2023

1) Accounting policies

The Charity is a Charitable Incorporated Organisation (CIO) registered in England & Wales and has no share capital. The charity's registered office address is Haematology - Bessemer Wing, Kings College Hospital, Denmark Hill, London SE5 9RS. Its charity number is 1145214.

Basis of preparation

The financial statements were prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS 102), effective 1 January 2019 - Charities SORP (FRS 102).

Assets and liabilities are recognised at historical cost or transaction value.

Preparation of accounts on a going concern basis.

The Trustees are satisfied that the CIO is a going concern and that these accounts should be prepared on that basis. With the continuing uncertain economic outlook the Trustees and CEO have put measures in place to extend and improve fundraising. The Trustees have considered the level of funds held and the expected level of income and expenditure for 12 months following the approval of these financial statements. The trustees have initiated a strategic review which will lead to the utilisation of excess reserves to improve and extend our activities.

Income Recognition

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 trustees are reasonably certain that they will receive it and the value can be reliably measured. Grants received without any restriction on entitlement are recognised in full upon award.

Legacy gifts are recognised following the granting of probate when the Charity has been notified in writing of both the amount and settlement date.

Donated professional services or facilities are recognised as income when the Charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), the general volunteer time of our team of volunteers is not recognised.

Interest on funds held on deposit is included when receivable and the amount can be measured reliably. All the charity's investment income arises from money held in interest bearing deposit accounts regulated by the Prudential Regulating Authority and covered by the Government's Financial Services Compensation Scheme (FSCS).

Resources expended

Liabilities are recognised as soon as there is a legal or constructive obligation committing the Charity to that expenditure, it is probable that settlement will be required and amount of the obligation can be measured reliably. 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.

Research Grants

Grants payable are payments made to third parties in furtherance of the charitable objects of the charity. In the case of an unconditional grant offer this is accrued once the recipient has been notified of the grant award. Provisions for grants are made where there is uncertainty as to the timing of the grant or the amount of grant payable.

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 10.

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 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.

Reserves

The Trustees have reviewed the policy on reserves considering the uncertainties around the impact of Covid 19 on our income and expenditure in the short and medium term. The Trustees have decided to use reserves to maintain our service levels and to meet new demands.

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 2023**2) Trustees' Remuneration**

The charity reimbursed Kings College Hospital Trust for emoluments of £34,913 and pension and NI contributions of £7,780 in respect of Sophie Wintrich, the Chief Executive. The other trustees neither received or waived any emoluments. The charity meets the expenses incurred by trustees in carrying out their duties. During the year no trustees had expenses met by the charity.

3) Donations, legacies and similar incoming resources.

	2023	2022
	£	£
Donations (including Gift Aid)	119,364	102,959
Legacies	260,000	308,253
	<u>379,364</u>	<u>411,212</u>

4) Grants

Takeda	0	650
Novartis	0	472
Janssen		
	<u>0</u>	<u>1,122</u>

5) Investment Income

Bank Interest Received	<u>4,075</u>	<u>700</u>
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6) Costs of raising funds

Advertising and promotion	2,139	-
Consultant	-	-
Event Costs	16,678	4,214
Donor database development/maintenance	3,602	1,410
Allocated staff costs	17,500	15,380
	<u>39,919</u>	<u>21,004</u>

7) Expenditure on charitable activities

Information and advocacy	20,273	10,628
Helpline	25,878	13,566
Local Patient support groups	20,438	10,714
National Forum	9,065	4,752
Conferences/representation	11,373	5,962
Patients survey	824	432
Website/social media	30,271	15,869
Clinical trials/advisory	7,747	4,061
Support costs	38,298	20,077
	<u>164,166</u>	<u>86,061</u>

8) Analysis of total expenditure

Reimbursed staff costs (1 secondee)	34,913	42,693
Salary, NI & pensions	95,797	43,793
Website	14,900	10,080
Literature and Information Sheets	-	-
Myelo's Hope MDS Animation	-	-
Local Support Groups		
Survey	-	-
Conference Participation		
Other costs	18,556	4,875
Governance costs	32	35
Fundraising costs	39,919	5,624
	<u>204,117</u>	<u>107,100</u>

Unaudited notes to the financial statements as at 31st March 2023

9) Staff Costs and Emoluments

	2023	2022
	£	£
Salaries	81,541	38,918
Social security costs	12,142	3,282
Pension costs	6,875	1,593
	<u>100,558</u>	<u>43,793</u>

10) Research Grant

Following a formal selection process Queens University Belfast was chosen to receive the first scientific research grant from the Charity to improve treatment for Myelodysplastic Syndrome.

The Charity awarded a grant of £173,046 to fund a four year PHD programme. A provision for the full amount of the grant was made in accordance with the Charities SORP (FRS 102). The project was completed in 2022. The unused portion of £1300.75 has been recognised in these accounts.

	2023	2022
	£	£
Payroll costs	0	523
Stationery and postage	57	192
Telephone and broadband	1,634	1,386
Office computer and software	828	1,812
Recruitment	6,235.20	600
Sundry expenses	576	362
Allocated administration costs	32,833	15,202
	<u>42,163</u>	<u>20,077</u>

12) Governance costs

AGM & governance meetings	32	35
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13) Taxation

The CIO is a registered charity with no liability to tax arising in the year.

14) Debtors

Gift Aid Recoverable	0	1,937
Prepayments	0	7,450
Other	1,328	-
	<u>1,328</u>	<u>9,387</u>

15) Current asset investments

Nationwide Building Society Deposit	-	-
CCLA Charities Deposit	86,143	84,613
Charity Bank Deposit	30,028	30,028
Co-Op Instant Access	3,061	65
Hampshire Trust	88,380	88,159
Redwood Bank Deposit	85,000	85,000
Scottish Widows Deposit	85,282	84,995
	<u>377,894</u>	<u>372,860</u>

16) Creditors

Paye		
Pension provider	560	269
Accruals	5,466	10,773
	<u>6,027</u>	<u>11,042</u>

17) Funds

Balance at 1st April 2022	606,264	189,937
Surplus for the year	197,930	416,327
	<u>804,194</u>	<u>606,264</u>
Unrestricted income funds at 31st March 2023		