

MDS UK PATIENT SUPPORT GROUP

England & Wales · Charity number 1145214

Details

Other names MDS Support UK

Status Registered

Legal form CIO

Registered 2011-12-22

Register [View on the Charity Commission register](#)

Contact

Address Springboard Business Centre
24 Ellerbrook Way
Stokesley Business Park
Stokesley
TS9 5LZ

Phone 02077337558

Email info@mdspatientsupport.org.uk

Website www.mdspatientsupport.org.uk

Activities

Objects: 1) TO RELIEVE SICKNESS AND PRESERVE, PROMOTE AND PROTECT HEALTH OF SUFFERERS OF MYELOYDYSPLASTIC SYNDROME (MDS) IN THE UNITED KINGDOM THROUGH THE PROVISION OF SUPPORT EDUCATION AND PRACTICAL ADVICE.2) TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC 0001IN THE UNITED KINGDOM IN ALL AREAS IN RELATION TO MDS.3) TO PROMOTE AND SUPPORT SCIENTIFIC RESEARCH INTO MDS, FOR THE TREATMENT OF MDS AND THE CARE OF SUFFERERS OF MDS, AND THOSE DISPOSED TO THE DEVELOPMENT OF SUFFERING MDS.

Activities: Support for those affected by Myelodysplastic Syndrome, ("MDS"), which is a rare blood cancer. We provide: national & regional meetings with specialist speakers, a website & newsletter, campaigning for access to treatment, a networking service for MDS patients to share experiences & support; cooperate with all UK MDS clinical experts; support clinical trials and research into MDS.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Northern Ireland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£254,314	£308,068	-	-
2024-03-31	£133,420	£226,050	-	-
2023-03-31	£402,047	£204,117	-	-
2022-03-31	£420,583	£107,100	-	-
2021-03-31	£180,512	£155,999	-	-

Trustees

Name	Role	Appointed
Linda Patricia Holder	Chair	2021-10-01
Atashia Maria Winnie Gonsalves		2024-03-21
Claudia Richards		2017-07-21
Kes Grant		2024-12-06
Lynda Elizabeth Harris		2025-03-06
Pauline Maeve MacRory		2024-04-13
Russell Cook		2015-01-23

MDS UK PATIENT SUPPORT GROUP

England & Wales - Charity number 1145214

Accounts

MDS UK PATIENT SUPPORT GROUP



Unaudited Financial Statements

Year ended 31st March 2025

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

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MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2025

The trustees submit their report together with the financial statements for the year ending 31st March 2025.

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

These are exciting times for MDS UK. The board of trustees are delighted to have appointed Blossom Bell as our CEO. Under her leadership, our small team continues to develop its range of support services, all designed to improve the lives of all those affected by MDS.

Blossom will continue and develop the important work undertaken by Debbie Hickman, our former Interim CEO, in supporting patients and their families, and for enhancing relations with a wider group of specialist haematologists. Significant challenges remain for a small charity such as ours particularly with fund-raising but also in providing support with such a small resource base for our communications and administration work, and the board will support Blossom to ensure that her strategic vision remains clear. Debbie has stood down from her role but continues to provide support. Many thanks to Debbie for her work over the last three years in first stabilising and then developing the work of MDS UK.

I have to thank all our volunteers, including our trustees, for their work in supporting our organisation and our members. Special thanks should go to Lin Holder who has been at the forefront of so many of the improvements to the back office systems, and gives freely of her time and energy. On behalf of MDS UK I send my best wishes to all our members, patients and their families as we continue to provide support to assist them in dealing with the personal consequences of their condition.

On a personal level, after four years of very rewarding work with the board and staff, the time is right for change both for me and the organisation and I will be stepping down before the next AGM.

Tony Allen Chair MDS UK Patient Support Group August 2025

Our purpose and activities

The Charity's principal activities during 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
- (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

1. Charitable Purpose

MDS UK's charitable purpose has two main strands:

- **To inform, support and empower** all those affected by rare blood cancers MDS and CMML, including patients, their families and caregivers
- **To represent MDS and CMML** within the clinical community; raising awareness, 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 include:

a) at patient/user level:

- Maintaining and growing a secure database of members
- Outreach to newly-diagnosed MDS/CMML patients and their families
- Facilitating member support meetings
- Circulating regular e-newsletters to members
- Facilitating online, subject-specific forums and Q & As, with guest speakers
- Maintaining an up-to-date, user-friendly website and social media platforms
- Producing up-to-date patient information literature and membership packs
- Providing a helpline and signposting service, by telephone and email
- Fundraising activities; liaising with, encouraging and supporting fundraisers including attending major events. Using fundraising activities to raise awareness of MDS and CMML

b) within the wider MDS community:

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

2. Achievements in 2024/25

The charity's main achievements in this financial year have been:

- Continued support and liaison for clinical trials REPAIR-MDS (Warwick University Clinical Trials Dept) and ASCELUS-H (Itecho – development of app for haematology patients)
- Providing funding and PPIE support for a new clinical study into the efficacy of Vitamin B5 to rescue red blood cell production in myelodysplasia
- The development and successful implementation of a new donor and member database
- Appointment of a retired Oncology and Nutrition CNS to help with member support
- A successful programme of speaker-led presentations and online support meetings
- 'Quick win', in-house improvements to website content, speed and navigation, and preparation for a new website in 2025/26
- Participation in national and international initiatives including Blood Cancer Awareness Month, MDS World Awareness Day; British Society of Haematology Conference, and the first MDS World Alliance in-person conference in Frankfurt.
- Design and dissemination of global MDS patient and caregiver survey
- Increased member numbers, both of main charity and private Facebook support group
- Participation in major charity fundraising events including Great North Run, Kiltwalk, and Cabbage Patch, raising funds but also increasing awareness of the conditions
- Participation in PPIE initiatives, including with Cambridge Centre for Cancer Research Genomics project guidelines.
- Appointment of several new Trustees with experience in governance, compliance, security and fundraising.
- The appointment of a new CEO, Blossom Bell, to take up the post on 1st May 2025.

3. Priorities for 2025/26

- Work closely with government health bodies, blood cancer, rare cancer and MDS alliances to ensure MDS and CMML are considered with the NHS 10 Year Plan and Cancer plan
- Establish direct relationships with pharmaceutical companies to develop new treatments
- Support earlier diagnosis, and consistency/quality of diagnosis delivery in MDS and CMML
- Introduce patient-centric workshops and training to increase psychological support
- Re-introduce in-person meetings and extend these to specialist centres around the UK.
- Conduct a full review and update of all patient literature, factsheets and website content

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2025

- Conduct a full audit to ensure GDPR compliance and donor data security
 - Commission and implement a new website
 - Complete Phase II functionality in new database
- Investigate opportunities with the NIHR to fun/part-fund educational bursaries and fellowships specifically for research into MDS/CMML

Debbie Hickman Interim CEO August 2025

Financial review

The following figures were taken from the full accounts approved on 30th August 2025. 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 - £254,314 Money spent - £305,408.

Money received: sources of funds

We received donations of £123,094 from members of the public and relatives of patients. This was an increase of almost 23% compared to last year.

We received legacy receipts, £92,024, We are extremely grateful to those who choose to recognise the work of the charity in this way.

Money spent:

Expenditure for the year of £305,408 (£226,050 – 2023/2024). This year's accounts report the costs of each of our charitable activities. The comparative figures are restated accordingly.

The deficit for the year of (£53,754) has been subtracted from the unrestricted reserves which now amount to £656,510. Our reserves are required to protect the charity from unexpected shocks and to be used to increase our support for patients and their families in line with our strategic objectives.

Going concern

At the time of this report, partly as a result of a number of large and unforeseen legacies received, MDS UK had unrestricted cash assets in excess of its liabilities, budget and contingency requirements. The trustees continue to develop plans to ensure that those resources are used to enhance and expand its services to its beneficiaries in accordance with its charitable objects.

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

Reference and administrative details

Charity number: 1145214
Registered Office: The Old Court House, New Road Avenue, Chatham, Kent, ME4 6BEJ
Office Address: Unit B.2 The Fuel Tank, 8-12 Creekside, London, SE8 3DX

Our Advisors

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

Bankers:

CAF Bank Ltd (Charities Aid Foundation)
Co-Operative Bank Ltd
Insignis Cash

Trustees

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

Russell Cook
Claudia Richards
Tony Allen
Lin Holder
Jen Goodison
Atashia Gonsalves
Maeve MacRory (appointed 13 April 2024)
Rev. Kes Grant (appointed 6 December 2024)
Lynda Harris (appointed 3 March 2025)
Chris Dugmore (resigned 12 March 2024)
Sirat Bhalla (resigned 18 September 2024)
Keith Hackett (resigned 20 May 2024)

Key management personnel:

Chief Executive: Debbie Hickman - Interim CEO

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 twelve.

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

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

Under charity law trustees must not approve the financial statements unless they give a true and fair view of the state of affairs of the charity 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 judgements 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 (Chair)

Date 30th August 2025

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

		2025	2024
		£	£
Income from	Note	Total	Total
Donations and similar incoming resources	3	123,094	100,108
Legacies	3	92,024	25,864
Investment income	5	39,196	5,907
Other income		-	1,541
Total income		254,314	133,420
Expenditure on			
Raising funds	6	102,689	56,514
Charitable activities	7	204,812	169,428
Governance costs	12	567	108
Total expenditure	8	308,068	226,050
Net income/deficit		(53,754)	(92,630)
Reconciliation of funds			
Total funds brought forward		710,264	802,894
Total funds carried forward		656,510	710,264

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

		2025 £ Total	2024 £ Total
Non-current assets			
Office furniture and fittings		8,172	8,172
Current assets			
Debtors	14	4,337	1,097
Current asset investments	15	593,220	656,684
Cash in bank and in hand		59,879	50,338
Liabilities: Amounts falling due within one year			
Creditors and accruals	16	9,098	9,267
Total Net Assets		656,510	707,024
The Funds of the Charity		656,510	707,024
Unrestricted Income Funds		656,510	707,024
Total Funds		656,510	707,024

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 The Old Court House, New Road Avenue, Chatham, Kent ME4 6BA. 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.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2025

Unaudited notes to the financial statements as at 31st March 2025

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

A research grant was made via Queen Mary's Paddington for initial trials into the value of Vitamin 5b to support MDS patients with anaemia.

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.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2025

Unaudited notes to the financial statements as at 31st March 2025

Reserves

The Trustees have reviewed the policy on reserves and our reserves are required to protect the charity from unexpected shocks and to be used to increase support for patients and their families in line with our strategic objectives.

Cash flow statement

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

2) Trustees' Remuneration

During the year no trustees had expenses, or payments, met by the charity

	Note	2025 £	2024 £
3) Donations, legacies and similar incoming resources			
Donations (including Gift Aid)		123,094	100,108
Legacies		92,024	25,864
Other income		-	1,541
		<u>215,118</u>	<u>127,513</u>
4) Grants			
No grant income was received		-	-
5) Investment income			
Investment and bank interest received		<u>39,196</u>	<u>5,907</u>

6) Cost of raising funds

Advertising and promotion	2,612	-
Consultant	1,375	2,675
Event costs	3,753	1,575
Donor database development/maintenance	26,134	22,043
Fundraising platform commission	2,669	563
Allocated staff costs	34,700	29,658
	71,243	56,514

7) Expenditure on charitable activities

Information and advocacy and outreach	25,398	21,964
Helpline	19,968	17,067
Local patient support groups	8,715	7,500
Conferences/representation	2,048	943
Website/social media	31,962	22,043
Clinical trials/advisory	-	-
Support costs	146,074	100,019
	234,165	169,536

8) Analysis of total expenditure

Reimbursed staff costs	-	15,810
Salary, NI and pensions	152,383	108,653
Rent and business rates	23,031	13,157
Website	31,963	22,043
Conference participation	2,048	943
Other costs	34,450	25,497
Governance costs	567	108
Fundraising costs	43,353	33,085
Legal expenses	17,603	6,754
	<u>305,408</u>	<u>226,050</u>

9) Staff costs and emoluments

Salaries	140,939	102,594
Social security costs	8,178	3,917
Pension costs	3,266	2,142
	<u>152,383</u>	<u>108,653</u>

10) Research grant

Research grant for trials on Vitamin B5	20,955	-
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11) Governance costs

AGM and governance meetings	<u>567</u>	<u>108</u>
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12) Taxation

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

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

13) Debtors

Gift Aid Recoverable	4,337	1,097
	<u>4,337</u>	<u>1,097</u>

14) Current asset investments

Insignis Cash	<u>593,220</u>	<u>656,684</u>
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15) Creditors

HMRC	3,535	3,535
Pension provider	640	640
Accruals	4,923	5,092
	<u>9,098</u>	<u>9,267</u>

16) Funds

Balance at 1st April 2024	710,264	802,894
Surplus/deficit for the year	(53,754)	(92,630)
	<u>656,510</u>	<u>710,264</u>

MDS UK PATIENT SUPPORT GROUP



Unaudited Financial Statements

Year ended 31st March 2025

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

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Report of the Chief Executive

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MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2025

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 - Complete Phase II functionality in new database
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Debbie Hickman Interim CEO August 2025

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Money spent:

Expenditure for the year of £305,408 (£226,050 – 2023/2024). This year's accounts report the costs of each of our charitable activities. The comparative figures are restated accordingly.

The deficit for the year of (£53,754) has been subtracted from the unrestricted reserves which now amount to £656,510. Our reserves are required to protect the charity from unexpected shocks and to be used to increase our support for patients and their families in line with our strategic objectives.

Going concern

At the time of this report, partly as a result of a number of large and unforeseen legacies received, MDS UK had unrestricted cash assets in excess of its liabilities, budget and contingency requirements. The trustees continue to develop plans to ensure that those resources are used to enhance and expand its services to its beneficiaries in accordance with its charitable objects.

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

Reference and administrative details

Charity number: 1145214
Registered Office: The Old Court House, New Road Avenue, Chatham, Kent, ME4 6BEJ
Office Address: Unit B.2 The Fuel Tank, 8-12 Creekside, London, SE8 3DX

Our Advisors

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

Bankers:

CAF Bank Ltd (Charities Aid Foundation)
Co-Operative Bank Ltd
Insignis Cash

Trustees

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

Russell Cook
Claudia Richards
Tony Allen
Lin Holder
Jen Goodison
Atashia Gonsalves
Maeve MacRory (appointed 13 April 2024)
Rev. Kes Grant (appointed 6 December 2024)
Lynda Harris (appointed 3 March 2025)
Chris Dugmore (resigned 12 March 2024)
Sirat Bhalla (resigned 18 September 2024)
Keith Hackett (resigned 20 May 2024)

Key management personnel:

Chief Executive: Debbie Hickman - Interim CEO

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 twelve.

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

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

Under charity law trustees must not approve the financial statements unless they give a true and fair view of the state of affairs of the charity 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 judgements 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 (Chair)

Date 30th August 2025

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

		2025	2024
		£	£
Income from	Note	Total	Total
Donations and similar incoming resources	3	123,094	100,108
Legacies	3	92,024	25,864
Investment income	5	39,196	5,907
Other income		-	1,541
Total income		254,314	133,420
Expenditure on			
Raising funds	6	102,689	56,514
Charitable activities	7	204,812	169,428
Governance costs	12	567	108
Total expenditure	8	308,068	226,050
Net income/deficit		(53,754)	(92,630)
Reconciliation of funds			
Total funds brought forward		710,264	802,894
Total funds carried forward		656,510	710,264

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

		2025 £ Total	2024 £ Total
Non-current assets	Note		
Office furniture and fittings		8,172	8,172
Current assets			
Debtors	14	4,337	1,097
Current asset investments	15	593,220	656,684
Cash in bank and in hand		59,879	50,338
Liabilities: Amounts falling due within one year			
Creditors and accruals	16	9,098	9,267
Total Net Assets		656,510	707,024
The Funds of the Charity		656,510	707,024
Unrestricted Income Funds	17	656,510	707,024
Total Funds		656,510	707,024

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 The Old Court House, New Road Avenue, Chatham, Kent ME4 6BA. 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.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2025

Unaudited notes to the financial statements as at 31st March 2025

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

A research grant was made via Queen Mary's Paddington for initial trials into the value of Vitamin 5b to support MDS patients with anaemia.

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.

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025
Unaudited notes to the financial statements as at 31st March 2025

Reserves

The Trustees have reviewed the policy on reserves and our reserves are required to protect the charity from unexpected shocks and to be used to increase support for patients and their families in line with our strategic objectives.

Cash flow statement

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

2) Trustees' Remuneration

During the year no trustees had expenses, or payments, met by the charity

	Note	2025 £	2024 £
3) Donations, legacies and similar incoming resources			
Donations (including Gift Aid)		123,094	100,108
Legacies		92,024	25,864
Other income		-	1,541
		<u>215,118</u>	<u>127,513</u>
4) Grants			
No grant income was received		-	-
5) Investment income			
Investment and bank interest received		<u>39,196</u>	<u>5,907</u>

6) Cost of raising funds

Advertising and promotion	2,612	-
Consultant	1,375	2,675
Event costs	3,753	1,575
Donor database development/maintenance	26,134	22,043
Fundraising platform commission	2,669	563
Allocated staff costs	34,700	29,658
	71,243	56,514

7) Expenditure on charitable activities

Information and advocacy and outreach	25,398	21,964
Helpline	19,968	17,067
Local patient support groups	8,715	7,500
Conferences/representation	2,048	943
Website/social media	31,962	22,043
Clinical trials/advisory	-	-
Support costs	146,074	100,019
	234,165	169,536

8) Analysis of total expenditure

Reimbursed staff costs	-	15,810
Salary, NI and pensions	152,383	108,653
Rent and business rates	23,031	13,157
Website	31,963	22,043
Conference participation	2,048	943
Other costs	34,450	25,497
Governance costs	567	108
Fundraising costs	43,353	33,085
Legal expenses	17,603	6,754
	<u>305,408</u>	<u>226,050</u>

9) Staff costs and emoluments

Salaries	140,939	102,594
Social security costs	8,178	3,917
Pension costs	3,266	2,142
	<u>152,383</u>	<u>108,653</u>

10) Research grant

Research grant for trials on Vitamin B5	20,955	-
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11) Governance costs

AGM and governance meetings	<u>567</u>	<u>108</u>
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12) Taxation

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

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2025

13) Debtors

Gift Aid Recoverable	4,337	1,097
	<u>4,337</u>	<u>1,097</u>

14) Current asset investments

Insignis Cash	<u>593,220</u>	<u>656,684</u>
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15) Creditors

HMRC	3,535	3,535
Pension provider	640	640
Accruals	4,923	5,092
	<u>9,098</u>	<u>9,267</u>

16) Funds

Balance at 1st April 2024	710,264	802,894
Surplus/deficit for the year	(53,754)	(92,630)
	<u>656,510</u>	<u>710,264</u>



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
MDS UK PATIENT SUPPORT GROUP

On accounts for the year
ended

31 MARCH 2025

Charity no
(if any)

1145214

Set out on pages

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/ 03 /2025**.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of The Association of Chartered Certified Accountants.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination.

Signed:

Date:

13/11/2025

Name:

MR OLUFEMI ALAKIJA FCCA

Relevant professional
qualification(s) or body
(if any):

ASSOCIATION OF CHARTERED CERTIFIED ACCOUNTANTS

Address:

THE OLD COURT HOUSE

NEW ROAD AVENUE

CHATHAM KENT ME4 6BE

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

Not applicable.

Accounts

MDS UK PATIENT SUPPORT GROUP

Unaudited Financial Statements
Year ended 31st March 2024

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2024

Index

Page Number	Description
2 - 9	Report of the Trustees
10	Unaudited Statement of Financial Activities
11	Unaudited Balance Sheet
12 - 19	Unaudited Notes to the Financial Statements

The trustees submit their report together with the financial statements for the year ending 31st March 2024.

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

The Board of Trustees of MDS UK believes the organisation is, at the end of March 2024, as strong as it has ever been.

Our objectives remain clear – to improve the lives of all those affected by MDS or CMML – and our strategic activities are now aligned to do this. Huge thanks are due to Debbie Hickman, our Interim CEO, and her small team for their work in supporting patients and their families, and for developing relations with a wider group of specialist haematologists, together with all the fundraising, communications and administration work necessary to support this, all of which are set out in the Chief Executive's report below.

I am sorry to report that Fiona Pirilla, our former secretary, died last year, as did Andy Veitch. Andy led the Kent Patient Support Group, was a committee member and CIO member of MDS UK, and for a while was acting chair before ill-health meant he had to step down. They both gave their support and service to MDS patients and both are sadly missed. My condolences to their families and all families who have lost loved ones to MDS or CMML during the past year.

Ted Peel, formerly chairman of trustees of MDS UK, resigned in March this year as a result of illness, but I am delighted that he remains involved in our work as one of our Patrons. Thank you also to John Evason and Alastair Day for their support, both of whom retired as trustees during the last year. We have been fortunate to have recruited a number of new trustees in recent months, who each bring something special to the Board and MDS UK. As a result I feel confident about the board's continued ability to lead the organisation through the next few years as we develop our support to MDS and CMML patients and their families.

I must end by thanking all our volunteers, including our trustees, for their work in supporting our organisation and our members, and on behalf of MDS UK I send my best wishes to all our members, patients and their families as we continue to provide support to assist them in dealing with the personal consequences of their condition.

Tony Allen
Chair MDS UK Patient Support Group
June 2024

Our purpose and activities

The Charity's principal activities during 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 suffers of MDS in the United Kingdom
- (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 suffers and those disposed to the development of MDS

Report of the Chief Executive

Objectives and achievements

1.Charitable Purpose

MDS UK's charitable purpose has two main strands:

The provision of support to those affected by rare blood cancers MDS and CMML, including patients, their families and caregivers.

To represent MDS and CMML within the clinical community; raising awareness, 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 include:

at patient/user level:

- Maintaining and growing a secure database of members
- Outreach to newly-diagnosed MDS/CMML patients and their families
- Facilitating member support meetings

- Circulating important information and regular e-newsletters to members
- Facilitating online, subject-specific forums and Q & As, with guest speakers
- Maintaining an up-to-date, user-friendly website and social media platforms
- Producing up-to-date patient information, factsheets and membership packs
- Providing a helpline and signposting service by telephone and email
- Managing fundraising activities; liaising with, encouraging and supporting fundraisers including attending major events.

within the wider MDS community:

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

2. Achievements in 2023/4

The charity's main achievements in this financial year have been:

- Introduction of a new telephone system to improve helpline management
- The design and development of a new database (phase 1 BETA version currently being tested, expected to be fully implemented June/July 2024)
- An increased number of speaker-led presentations and member participation
- Increased member numbers, both of main charity and private Facebook support group
- The appointment of a Project Worker to work with Interim CEO in improving clinician engagement, reviewing and improving services to members, and conducting a full audit of all patient literature and website content to ensure it is fit for purpose.
- Support and liaison for clinical trials REPAIR-MDS (Warwick University Clinical Trials Dept) and ASCELUS-H (Itecho – development of app for haematology patients)
- Publishing a revised edition of the MDS Patient Guide, in conjunction with Leukaemia Care
- Moving to new office premises to improve working conditions for staff
- A full website audit and formulation of a plan for future restructuring
- 'Quick win', in-house improvements to website content, speed and navigation
- Participation in national and international initiatives including Blood Cancer Awareness Month, MDS World Awareness Day; exhibited at British Society of Haematology conference.

- Participation in major charity fundraising events including Great North Run, Kiltwalk, and Cabbage Patch.

3. Operations

Following a period of illness and bereavement, CEO Sophie Wintrich took extended leave from April 2023 to October 2023 and subsequently resigned from the post (previously a secondment from Kings College Hospital but now been brought in-house). The Interim CEO was appointed in May 2023 to oversee operations during the CEO's absence and continues to steer the charity until a permanent replacement is found (recruitment is underway April 2024).

A Risk and Audit sub-committee was established in 2023/24 and has undertaken a full review of the charity's financial arrangements and governance. Quarterly meetings of the R & AC take place, which include ongoing reviews of the charity's risk register, policies and procedures.

4. Priorities for the charity in 2024/25

- Appoint a permanent Chief Executive Officer
- Continue to review and update all information factsheets
- Expand outreach activities, to engage more clinicians and grow membership
- Introduce member focus groups to identify further needs
- Agree policy on funding and supporting research projects
- Consider and implement new branding and logo
- Complete test of new database, with implementation of Phase I by July 2024
- Identify requirements for Phase II of new database
- Implement changes from full website audit, delete and rewrite content as necessary
- Review structure of current website and consider full replacement
- Review and agree upon fundraising strategy going forward.

Debbie Hickman,
Interim CEO
June 2024

Financial review

The following figures were taken from the full accounts approved on 30th August 2024. 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 - £133,420 Money spent - £226,050.

Money received: sources of funds

We received donations of £100,108 from members of the public and relatives of patients. This was a decrease of 16.13% compared to last year.

We received a small number of legacy receipts, £25,867, We are extremely grateful to those who choose to recognise the work of the charity in this way.

Money spent:

Expenditure for the year of £226,050 (£204,117 - 2022/23). This year's accounts report the costs of each of our charitable activities. The comparative figures are restated accordingly.

The deficit for the year of (£92,627) has been subtracted from the unrestricted reserves which now amount to £710,264. Our reserves are required to protect the charity from unexpected shocks and to be used to increase our support for patients and their families in line with our strategic objectives.

Going concern

At the time of this report, partly as a result of a number of large and unforeseen legacies received, MDS UK had unrestricted cash assets in excess of its liabilities, budget and contingency requirements. The trustees continue to develop plans to ensure that those resources are used to enhance and expand its services to its beneficiaries in accordance with its charitable objects.

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Trustees

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

Russell Cook
Claudia Richards
Tony Allen
Lin Holder
John Evason (resigned 1 December 2023)
Alastair Day (resigned 6 October 2023)
Edward Peel (resigned 31 March 2024)
Sophie Wintrich (resigned 28th April 2023)
Chris Dugmore (appointed 20 March 2023)
Sirat Bhalla (appointed 10 January 2024)
Keith Hackett (appointed 8 March 2024)
Jen Goodison (appointed 8 March 2024)
Atashia Gonsalves (appointed 21 March 2024)

Key management personnel:

Chief Executive: Debbie Hickman - Interim CEO

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 twelve.

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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.

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Under charity law trustees must not approve the financial statements unless they give a

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2024

true and fair view of the state of affairs of the charity 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 judgements 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 (Chair)

Date 30th August 2024

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2024

		2024	2023
		£	£
Income from	Note	Total	Total
Donations and similar incoming resources	3	100,108	119,364
Legacies	3	25,864	260,000
Grants	4	-	-
Investment income	5	5,907	4,075
Other income		1,541	18,608
Total income		133,420	402,047
Expenditure on			
Raising funds	6	56,514	39,919
Charitable activities	7	169,428	164,166
Governance costs	12	108	32
Total expenditure	8	226,050	204,117
Write back of Provision for Research grant	10	-	1,301
Net income/deficit		(92,630)	196,630
Reconciliation of funds			
Total funds brought forward		802,894	606,264
Total funds carried forward		710,264	802,894

		2024 £ Total	2023 £ Total
Non-current assets	Note		
Office furniture and fittings		8,172	-
Current assets			
Debtors	14	1,097	1,328
Current asset investments	15	656,684	377,894
Cash in bank and in hand		50,338	429,699
Liabilities: Amounts falling due within one year			
Creditors and accruals	16	9,267	6,027
Total Net Assets		707,024	802,894
The Funds of the Charity		707,024	802,894
Unrestricted Income Funds	17	707,024	802,894
Total Funds		707,024	802,894

Unaudited notes to the financial statements as at 31st March 2024

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 The Old Court House, New Road Avenue, Chatham, Kent ME4 6BA. Its charity number is 1145214.

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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.

Unaudited notes to the financial statements as at 31st March 2024

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

No further research grants were agreed during the period of these accounts.

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.

Unaudited notes to the financial statements as at 31st March 2024

Reserves

The Trustees have reviewed the policy on reserves and our reserves are required to protect the charity from unexpected shocks and to be used to increase support for patients and their families in line with our strategic objectives.

Cash flow statement

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

2) Trustees' Remuneration

The charity reimbursed King's College University Hospital Trust for emoluments of £15,820 in total for pension and employers' National Insurance in respect of Sophie Wintrich, the former 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 one trustee had expenses met by the charity for £15.

	Note	2024 £	2023 £
3) Donations, legacies and similar incoming resources			
Donations (including Gift Aid)		100,108	119,634
Legacies		25,864	260,000
Other income (honorary received)		1,541	-
		<u>127,513</u>	<u>379,364</u>
4) Grants			
No grant income was received		-	-
5) Investment income			
Investment and bank interest received		<u>5,907</u>	<u>4,075</u>

6) Cost of raising funds

Advertising and promotion	-	2,139
Consultant	2,675	-
Event costs	1,575	16,678
Donor database development/maintenance	22,043	3,602
Fundraising platform commission	563	-
Allocated staff costs	29,658	17,500
	<u>56,514</u>	<u>39,919</u>

7) Expenditure on charitable activities

Information and advocacy and outreach	21,964	20,273
Helpline	17,067	25,878
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Support costs	100,019	38,298
	<u>169,536</u>	<u>164,167</u>

8) Analysis of total expenditure

Reimbursed staff costs (1 secondee to 11 Aug 2024)	15,810	34,913
Salary, NI and pensions	9 108,653	95,797
Rent and business rates	13,157	-
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Other costs	25,497	18,556
Governance costs	108	32
Fundraising costs	33,085	39,919
Legal expenses	6,754	-
	<u>226,050</u>	<u>204,117</u>

9) Staff costs and emoluments

Salaries	102,594	81,541
Social security costs	3,917	12,142
Pension costs	2,142	6,875
	<u>108,653</u>	<u>100,558</u>

10) Research grant

No further grants had been provided	10	-	-
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11) Governance costs

AGM and governance meetings	<u>108</u>	<u>32</u>
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12) Taxation

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

13) Debtors

Gift Aid Recoverable	4,337	-
Other	-	1,328
	<u>4,337</u>	<u>1,328</u>

14) Current asset investments

Insignis Cash	<u>656,684</u>	<u>377,894</u>
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16) Creditors

HMRC	3,535	-
Pension provider	640	560
Accruals	<u>5,092</u>	<u>5,466</u>
	<u>9,267</u>	<u>6,026</u>

17) Funds

Balance at 1st April 2023	802,894	606,264
Surplus/deficit for the year	<u>(92,630)</u>	<u>196,630</u>
	<u>710,264</u>	<u>802,894</u>

MDS UK PATIENT SUPPORT GROUP

Unaudited Financial Statements
Year ended 31st March 2024

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2024

Index

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2 - 9	Report of the Trustees
10	Unaudited Statement of Financial Activities
11	Unaudited Balance Sheet
12 - 19	Unaudited Notes to the Financial Statements

The trustees submit their report together with the financial statements for the year ending 31st March 2024.

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

The Board of Trustees of MDS UK believes the organisation is, at the end of March 2024, as strong as it has ever been.

Our objectives remain clear – to improve the lives of all those affected by MDS or CMML – and our strategic activities are now aligned to do this. Huge thanks are due to Debbie Hickman, our Interim CEO, and her small team for their work in supporting patients and their families, and for developing relations with a wider group of specialist haematologists, together with all the fundraising, communications and administration work necessary to support this, all of which are set out in the Chief Executive's report below.

I am sorry to report that Fiona Pirilla, our former secretary, died last year, as did Andy Veitch. Andy led the Kent Patient Support Group, was a committee member and CIO member of MDS UK, and for a while was acting chair before ill-health meant he had to step down. They both gave their support and service to MDS patients and both are sadly missed. My condolences to their families and all families who have lost loved ones to MDS or CMML during the past year.

Ted Peel, formerly chairman of trustees of MDS UK, resigned in March this year as a result of illness, but I am delighted that he remains involved in our work as one of our Patrons. Thank you also to John Evason and Alastair Day for their support, both of whom retired as trustees during the last year. We have been fortunate to have recruited a number of new trustees in recent months, who each bring something special to the Board and MDS UK. As a result I feel confident about the board's continued ability to lead the organisation through the next few years as we develop our support to MDS and CMML patients and their families.

I must end by thanking all our volunteers, including our trustees, for their work in supporting our organisation and our members, and on behalf of MDS UK I send my best wishes to all our members, patients and their families as we continue to provide support to assist them in dealing with the personal consequences of their condition.

Tony Allen
Chair MDS UK Patient Support Group
June 2024

Our purpose and activities

The Charity's principal activities during 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
- (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

1.Charitable Purpose

MDS UK's charitable purpose has two main strands:

The provision of support to those affected by rare blood cancers MDS and CMML, including patients, their families and caregivers.

To represent MDS and CMML within the clinical community; raising awareness, 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 include:

at patient/user level:

- Maintaining and growing a secure database of members
- Outreach to newly-diagnosed MDS/CMML patients and their families
- Facilitating member support meetings

- Circulating important information and regular e-newsletters to members
- Facilitating online, subject-specific forums and Q & As, with guest speakers
- Maintaining an up-to-date, user-friendly website and social media platforms
- Producing up-to-date patient information, factsheets and membership packs
- Providing a helpline and signposting service by telephone and email
- Managing fundraising activities; liaising with, encouraging and supporting fundraisers including attending major events.

within the wider MDS community:

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

2. Achievements in 2023/4

The charity's main achievements in this financial year have been:

- Introduction of a new telephone system to improve helpline management
- The design and development of a new database (phase 1 BETA version currently being tested, expected to be fully implemented June/July 2024)
- An increased number of speaker-led presentations and member participation
- Increased member numbers, both of main charity and private Facebook support group
- The appointment of a Project Worker to work with Interim CEO in improving clinician engagement, reviewing and improving services to members, and conducting a full audit of all patient literature and website content to ensure it is fit for purpose.
- Support and liaison for clinical trials REPAIR-MDS (Warwick University Clinical Trials Dept) and ASCELUS-H (Itecho – development of app for haematology patients)
- Publishing a revised edition of the MDS Patient Guide, in conjunction with Leukaemia Care
- Moving to new office premises to improve working conditions for staff
- A full website audit and formulation of a plan for future restructuring
- 'Quick win', in-house improvements to website content, speed and navigation
- Participation in national and international initiatives including Blood Cancer Awareness Month, MDS World Awareness Day; exhibited at British Society of Haematology conference.

- Participation in major charity fundraising events including Great North Run, Kiltwalk, and Cabbage Patch.

3. Operations

Following a period of illness and bereavement, CEO Sophie Wintrich took extended leave from April 2023 to October 2023 and subsequently resigned from the post (previously a secondment from Kings College Hospital but now been brought in-house). The Interim CEO was appointed in May 2023 to oversee operations during the CEO's absence and continues to steer the charity until a permanent replacement is found (recruitment is underway April 2024).

A Risk and Audit sub-committee was established in 2023/24 and has undertaken a full review of the charity's financial arrangements and governance. Quarterly meetings of the R & AC take place, which include ongoing reviews of the charity's risk register, policies and procedures.

4. Priorities for the charity in 2024/25

- Appoint a permanent Chief Executive Officer
- Continue to review and update all information factsheets
- Expand outreach activities, to engage more clinicians and grow membership
- Introduce member focus groups to identify further needs
- Agree policy on funding and supporting research projects
- Consider and implement new branding and logo
- Complete test of new database, with implementation of Phase I by July 2024
- Identify requirements for Phase II of new database
- Implement changes from full website audit, delete and rewrite content as necessary
- Review structure of current website and consider full replacement
- Review and agree upon fundraising strategy going forward.

Debbie Hickman,
Interim CEO
June 2024

Financial review

The following figures were taken from the full accounts approved on 30th August 2024. 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 - £133,420 Money spent - £226,050.

Money received: sources of funds

We received donations of £100,108 from members of the public and relatives of patients. This was a decrease of 16.13% compared to last year.

We received a small number of legacy receipts, £25,867, We are extremely grateful to those who choose to recognise the work of the charity in this way.

Money spent:

Expenditure for the year of £226,050 (£204,117 - 2022/23). This year's accounts report the costs of each of our charitable activities. The comparative figures are restated accordingly.

The deficit for the year of (£92,627) has been subtracted from the unrestricted reserves which now amount to £710,264. Our reserves are required to protect the charity from unexpected shocks and to be used to increase our support for patients and their families in line with our strategic objectives.

Going concern

At the time of this report, partly as a result of a number of large and unforeseen legacies received, MDS UK had unrestricted cash assets in excess of its liabilities, budget and contingency requirements. The trustees continue to develop plans to ensure that those resources are used to enhance and expand its services to its beneficiaries in accordance with its charitable objects.

Reference and administrative details

Charity number: 1145214
Registered Office: The Old Court House, New Road Avenue, Chatham, Kent, ME4 6BEJ
Office Address: Unit B.2 The Fuel Tank, 8-12 Creekside, London, SE8 3DX

Our Advisors

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

Bankers:

CAF Bank Ltd (Charities Aid Foundation)
Co-Operative Bank Ltd
Insignis Cash

Trustees

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

Russell Cook
Claudia Richards
Tony Allen
Lin Holder
John Evason (resigned 1 December 2023)
Alastair Day (resigned 6 October 2023)
Edward Peel (resigned 31 March 2024)
Sophie Wintrich (resigned 28th April 2023)
Chris Dugmore (appointed 20 March 2023)
Sirat Bhalla (appointed 10 January 2024)
Keith Hackett (appointed 8 March 2024)
Jen Goodison (appointed 8 March 2024)
Atashia Gonsalves (appointed 21 March 2024)

Key management personnel:

Chief Executive: Debbie Hickman - Interim CEO

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 twelve.

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

Under charity law trustees must not approve the financial statements unless they give a

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2024

true and fair view of the state of affairs of the charity 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 judgements 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 (Chair)

Date 30th August 2024

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP
Report of the Trustees for the year ended 31st March 2024

		2024	2023
		£	£
Income from	Note	Total	Total
Donations and similar incoming resources	3	100,108	119,364
Legacies	3	25,864	260,000
Grants	4	-	-
Investment income	5	5,907	4,075
Other income		1,541	18,608
Total income		133,420	402,047
Expenditure on			
Raising funds	6	56,514	39,919
Charitable activities	7	169,428	164,166
Governance costs	12	108	32
Total expenditure	8	226,050	204,117
Write back of Provision for Research grant	10	-	1,301
Net income/deficit		(92,630)	196,630
Reconciliation of funds			
Total funds brought forward		802,894	606,264
Total funds carried forward		710,264	802,894

		2024 £ Total	2023 £ Total
Non-current assets	Note		
Office furniture and fittings		8,172	-
Current assets			
Debtors	14	1,097	1,328
Current asset investments	15	656,684	377,894
Cash in bank and in hand		50,338	429,699
Liabilities: Amounts falling due within one year			
Creditors and accruals	16	9,267	6,027
Total Net Assets		707,024	802,894
The Funds of the Charity		707,024	802,894
Unrestricted Income Funds	17	707,024	802,894
Total Funds		707,024	802,894

Unaudited notes to the financial statements as at 31st March 2024

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 The Old Court House, New Road Avenue, Chatham, Kent ME4 6BA. 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.

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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.

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AGM and governance meetings	<u>108</u>	<u>32</u>
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Surplus/deficit for the year	<u>(92,630)</u>	<u>196,630</u>
	<u>710,264</u>	<u>802,894</u>



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
MDS UK PATIENT SUPPORT GROUP

On accounts for the year
ended

31 MARCH 2024

Charity no
(if any)

1145214

Set out on pages

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/ 03 /2024**.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of The Association of Chartered Certified Accountants.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination.

Signed:

Date:

31/03/2024

Name:

MR OLUFEMI ALAKIJA FCCA

Relevant professional
qualification(s) or body
(if any):

ASSOCIATION OF CHARTERED CERTIFIED ACCOUNTANTS

Address:

THE OLD COURT HOUSE

NEW ROAD AVENUE

CHATHAM KENT ME4 6BE

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

Not applicable.

Accounts

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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12	Unaudited Balance Sheet
13 to 16	Unaudited Notes to the Financial Statements

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

MDS UK PATIENT SUPPORT GROUP

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;

MDS UK PATIENT SUPPORT GROUP

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

- 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

MDS UK PATIENT SUPPORT GROUP

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

MDS UK PATIENT SUPPORT GROUP

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)

MDS UK PATIENT SUPPORT GROUP

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

MDS UK PATIENT SUPPORT GROUP

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

MDS UK PATIENT SUPPORT GROUP

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>

Note 11

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>

Note 12

Note 6

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		

Accounts

MDS UK PATIENT SUPPORT GROUP

Unaudited Financial Statements

Year ended 31st March 2022

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2022

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12	Unaudited Balance Sheet
13 to 16	Unaudited Notes to the Financial Statements

Registered Charity Number: 1145214

Report of the Trustees for the year ended 31st March 2022

The trustees, submit their report together with the financial statements for the year ending 31st March 2022

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

The COVID pandemic once again dominated the agenda for our charity during the year under review. Our staff and volunteers have worked hard to provide information and reassurance to our members, and Sophie Wintrich, our CEO, worked successfully with the NHS to ensure that MDS and CMML patients were recognised as being vulnerable, and as a result provided with additional advice and support by the NHS and its systems. Sadly, while it is understandable that government wants to put COVID 19 behind us, our members and their families will continue to be vulnerable, and MDS UK will continue its work to ensure that support remains available. Feedback from members and their families during the last year indicates that our services and support continue to be very well received, in particular since the COVID pandemic and the increased introduction of remote clinical consultations. Maintaining our communications and inviting members to online meetings has been a priority, but at huge personal cost to staff and volunteers. It became increasingly clear to us during the year that we needed more paid staff and volunteers to continue to meet our members' needs. Fortunately, our fund-raising efforts have enabled us to survive the year with a healthy surplus, which can now be used to enable us to plan effectively for the future. Our strategy for the future is to build on these successes and continue to ensure that MDS UK provides information and support that meets each of our members' needs. This requires investment in skilled staff and IT support, which is in course of being developed. Our ultimate aim is that all newly diagnosed MDS and CMML patients are directed to, and able to access, our services, and that these continue to support all our members.

In 2020 the Trustees decided to support a research programme at Queens University Belfast, in the hope that the outcome would be of significant value to the detection and treatment of the disease. This decision was undertaken in the knowledge that research can be inherently risky, and sadly we have learnt that the research programme that we were supporting has had to be terminated. Sixty percent of the funds offered to support the research has not been spent, and we are now able to redirect these funds to other uses. It is unlikely in the short term that we will be supporting research at the same level, since the resources we need to improve our staff levels and systems has to be a priority for the time being.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2022

It is normal at this time for me to thank our staff and volunteers for the work they do, but, particularly this year, it is important to remember how hard they have had to work to continue to provide services and support against all the issues and concerns thrown up by the pandemic and pressures on the NHS. I would like to thank our patient support ambassadors, funds raisers, supporters and trustees for the efforts they have made to enable us not only to survive, but emerge stronger from a very difficult year

On a personal note, I am honoured to have been asked to act as chairman, while the Chairman of MDS UK, Ted Peel, continues to undergo treatment; I send him good wishes from all the trustees and members of the former committee for his continued recovery.

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 Chairman
September 2022

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

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;

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2022

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. At patient/user level:

Maintaining a database of members
Organising/running patient support meetings
Publishing and circulating a monthly newsletter to members
Organising/running subject-specific forums with speakers
Providing an up-to-date, user-friendly website, and social media platforms
Managing a user-friendly member chat forum hosted on website
Producing patient information literature and membership packs
Providing a helpline and signposting service, by telephone and email
Providing patient advocacy where feasible/relevant.

2. within the 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:

- Involvement in the SOAP study (COVID-specific trial at Kings College Hospital)
- Providing support to an increasing member/user base despite Covid-19 restrictions
- An increased number of well-received online meetings, and webinar-style presentations by leading haematologists
- The appointment of an experienced website content manager, improving online functions and ensuring timely, up to date information available to patients and clinicians
- PPI work with British Society of Haematology (Revised Treatment Guidelines for MDS)
- Bio-banking committee (Kings College Hospital)
- Involvement in launch of REPAIR-MDS trial (Warwick University Clinical Trials Team)
- Joint participation in Blood Cancer Awareness Month
- Media awareness and fundraising activities for MDS World Awareness Day
- Campaigns re drug availability (Luspatercept, Exjade)
- 'Cancer/Not Cancer?' – campaigning for consistency and clarification in MDS diagnosis

Operations

The charity conducts a full review of systems and processes each year, and sets aims and objectives for the coming period. The charity had managed to fulfil its main objectives,

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2022

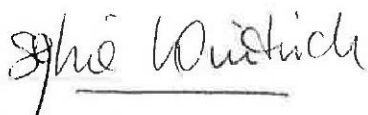
continuing to provide support to patients and full participation in clinical work, all through the pandemic, and the personnel were thanked for their efforts in this regard. Although most Covid-19 related workplace restrictions had eased, it was agreed to continue with on-line meetings given the vulnerability of patient members and volunteer ambassadors, many of whom are patients themselves. The online meetings/speaker presentations had proved to be very successful, and will continue to be offered, even if face-to-face support meetings can resume at some stage in the future.

New office premises are being actively sought, to make provision should the existing office space cease to be available once the KCH haematology department is relocated (anticipated in 2023/24). Suitable premises have been identified and a memorandum of understanding is in the process of being agreed.

To continue to further build upon its activities and support services to its users, and to allow the CEO more time to concentrate on higher-level activities as detailed above, the Trustees agreed to recruit an Operations Manager. An appointment was made in June 2022. This will be for an initial six-month period, to allow for further review later in the year.

Fundraising: in line with other charities, this has been heavily curbed during Covid-19, however many major events look set to resume in 2022/23. The charity appointed a new, full-time Fundraising Officer in May 2022

The charity continues to operate with all staff working from home, with a possible, partial return to office-based working anticipated in late 2022/early 2023.



Sophie Wintrich
Chief Executive

Financial Review

The following figures were taken from the full accounts approved on 18th November. 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 - £420,583. Money spent - £107,100

It has been an extraordinary year. Two large legacies and the termination of the Research programme contributed to a surplus of £416,327 compared to surplus of £24,513 in 2020/21.

Money received: sources of funds

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2022

We received donations of £102,959 from members of the public and relatives of patients. This is down 31% compared to last year. A grant of £650 was received from Takeda and £472 from Janssen. Both were unrestricted and complied with the Code of Practice for the UK Pharmaceutical Industry.

We were fortunate to receive two very large legacies during the year amounting to £308,253 (2020/21 £15,151). 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 amounting to £102,844.

Money spent:

Expenditure for the year of £107,100 (£155,999 2020/21). This year's accounts report the costs of each of our charitable activities as the introduction of timesheets in the previous year has enabled staff costs to be allocated to each activity. The comparative figures have been restated accordingly. Staff costs were lower due to an employee who left and was not replaced until 2022/23. This reduced the allocation to charitable activities especially information and advocacy and website/social media. There has also been an increase in time given by the trustees and volunteers at no cost to the charity.

The surplus for the year of £416,327 has been added to unrestricted reserves which now amount to £606,264. 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 impact of COVID-19 on the ability of the charity to raise funds and the increase in demand for our services. The trustees have considered continued uncertainty due to Covid 19, the level of funds held, and the expected level of income and expenditure for the 12 months following the approval of these financial statements. They have concluded that the budgeted income and expenditure with the existing level of free reserves is sufficient for 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.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2022

Our Advisors

Examiner: David King, FCA The Dell, Old Farm Rd, Hampton, TW12 3RJ

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
Don Barrett
Russell Cook
Chris Charlwood
Fiona Pirilla (resigned 21st May 2021)
Claudia Richards
Tony Allen (appointed 1st October 2021)
Lin Holder (appointed 1st October 2021)

Key management personnel:

Chief Executive: Sophie Wintrich

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.

Report of the Trustees for the year ended 31st March 2022

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. This is an especially important exercise at the current time in view of the risks surrounding COVID-19. 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 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.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2022

(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

Unaudited Statement of Financial Activities (Incorporating Income and Expenditure Account) for the year ended 31st March, 2022.

		2022	2021
		£	£
	Note	Total	Total
Income from			
Donations and similar incoming resources	3	102,959	148,298
Legacies	3	308,253	15,151
Grants	4	1,122	10,750
Investment income	5	700	1,104
Other Income		<u>7,549</u>	<u>5,209</u>
Total income		<u>420,583</u>	<u>180,512</u>
Expenditure on			
Raising Funds	6	21,004	23,903
Charitable activities	7	86,061	132,096
Governance Costs	12	<u>35</u>	<u>-</u>
Total expenditure	8	<u>107,100</u>	<u>155,999</u>
Write back of Provision for Research grant	10	-102,844	-
Net income		<u>416,327</u>	<u>24,513</u>
Reconciliation of funds			
Total funds brought forward		189,937	165,424
Total funds carried forward		<u><u>606,264</u></u>	<u><u>189,937</u></u>

All amounts relate to continuing activities

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

Unaudited Balance sheet
As at 31st March 2022.

		2022	2021
		£	£
	Note	Total	Total
Current assets:			
Debtors	14	9,387	7,199
Current asset investments	15	372,860	298,526
Cash at bank and in hand		244,064	42,835
Liabilities: Amounts falling due within one year			
Creditors and accruals	16	-11,042	-15,091
Total Net Assets		615,269	333,469
Provision for research grant	10	9,005	143,532
The Funds of the Charity		606,264	165,424
Unrestricted income funds	17	606,264	189,937
Total funds		606,264	189,937

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

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 11.

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 to respond to Covid 19. We expect to incur a surplus for the year ending 31 March 2023. The trustees have initiated a strategic review which will lead to the utilisation of excess reserves to improve and extend our activities.

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 2022

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.

	2022 £	2021 £
Donations (including Gift Aid)	102,959	148,298
Legacies	308,253	15,151
	<u>411,212</u>	<u>163,449</u>

4) Grants

Takeda	650	-
Novartis	-	750
Janssen	472	10,000
	<u>1,122</u>	<u>10,750</u>

5) Investment Income

Bank Interest Received	<u>700</u>	<u>1,104</u>
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6) Costs of raising funds

Advertising and promotion	-	1,070
Consultant	-	2,260
Event Costs	4,214	622
Donor database development/maintenance	1,410	2,760
Allocated staff costs	15,380	17,191
	<u>21,004</u>	<u>23,903</u>

7) Expenditure on charitable activities

Information and advocacy	10,628	36,893
Helpline	13,566	22,996
Local Patient support groups	10,714	11,624
National Forum	4,752	-
Conferences/representation	5,962	8,149
Patients survey	432	1,411
Website/social media	15,869	23,375
Clinical trials/advisory	4,061	4,354
Support costs	20,077	23,294
	<u>86,061</u>	<u>132,096</u>

8) Analysis of total expenditure

Reimbursed staff costs (1 secondee)	42,693	44,658
Salary, NI & pensions	43,793	66,974
Website	10,080	11,765
Literature and Information Sheets	-	3,066
Myelo's Hope MDS Animation	-	14,975
Local Support Groups	-	14
Survey	-	853
Conference Participation	-	-
Other costs	4,875	6,982
Governance costs	35	-
Fundraising costs	5,624	6,712
	<u>107,100</u>	<u>155,999</u>

Unaudited notes to the financial statements as at 31st March 2022

9) Staff Costs and Emoluments

	2022	2021
	£	£
Salaries	38,918	60,380
Social security costs	3,282	4,940
Pension costs	1,593	1,654
	<u>43,793</u>	<u>66,974</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 terminated in September 2022. The unused portion of £102,851 has been recognised as a significant post balance sheet event in these accounts.

	2022	2021
	£	£
Payroll costs	523	616
Stationery and postage	192	251
Telephone and broadband	1,386	1,128
Office computer and software	1,812	3,377
Recruitment	600	-
Sundry expenses	362	2,070
Allocated administration costs	15,202	15,852
	<u>20,077</u>	<u>23,294</u>

12) Governance costs

AGM & governance meetings	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	1,937	5,729
Prepayments	7,450	1,350
Other	-	120
	<u>9,387</u>	<u>7,199</u>

15) Current asset investments

Nationwide Building Society Deposit	-	75,958
CCLA Charities Deposit	84,613	48,609
Charity Bank Deposit	30,028	-
Co-Op Instant Access	65	65
Hampshire Trust	88,159	87,939
Redwood Bank Deposit	85,000	10,000
Scottish Widows Deposit	84,995	75,955
	<u>372,860</u>	<u>298,526</u>

16) Creditors

Paye		325
Pension provider	269	-
Accruals	10,773	14,766
	<u>11,042</u>	<u>15,091</u>

17) Funds

Balance at 1st April 2021	189,937	165,424
Surplus for the year	416,327	24,513
Unrestricted income funds at 31st March 2022	<u>606,264</u>	<u>189,937</u>

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

I report to the charity's trustees on my examination of the accounts of the charity for the year ended 31 March 2022.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

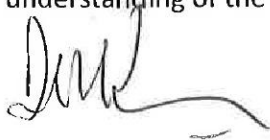
I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

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

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.



D H King BSc FCA
Chartered Accountant
The Dell,
Old Farm Road
Hampton, Middlesex, TW12 3RJ

20 December 2022

Accounts

MDS UK PATIENT SUPPORT GROUP

Unaudited Financial Statements

Year ended 31st March 2021

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

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13	Unaudited Statement of Financial Activities
14	Unaudited Balance Sheet
15 to 18	Unaudited Notes to the Financial Statements

Registered Charity Number: 1145214

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

The trustees, submit their report together with the financial statements for the year ending 31st March 2021.

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

The past year has been one of considerable achievement for the Charity. However, our achievements were sadly overshadowed at the end of the financial year by the effect of the Covid-19 pandemic which has placed a major burden on our financial resources.

Last year we set ourselves a number of strategic targets aimed at strengthening the Charity and broadening our range of activities for the benefit of our members. A major commitment was that of entering the field of clinical research. Such an undertaking had been discussed at length by our Central Board. A major consideration was that of finance, as sponsorship of research is extremely expensive, plus the likelihood of a positive outcome is always uncertain. Taking these factors into consideration, we decided that as it was something that many of those suffering from MDS had asked for, it was a rational way to use our financial reserves. Following the advertising of the proposed Ph.D. research, we received several suitable applications and after careful analysis of the proposed research, assisted by haematological clinicians, a decision was made to award the project to Queen Mary's College, Belfast University. A major reason for the award was that the research was to be based on the repair of damaged DNA, which occurs in all blood cancers. Thus, a positive outcome from the research could have significant implications for the treatment of blood cancers. A Ph.D. student was subsequently selected by the University and commenced the research in January 2020. Our Charity was congratulated by Professor Mufti (Head of Haematology at Kings College Hospital) for taking this significant step into clinical research. Unfortunately, the spread of Covid-19 has delayed the progression of the research.

With the assistance of a specialist fundraising company and following a careful analysis of our previous fundraising initiatives and that of similar Charities, a broad fundraising strategy was designed and, prior to the interruption of the pandemic, was being followed. The fundraising company also advised on the selection of a Fundraising Officer. Utilising our financial reserves, the selected individual was recruited as an employee with the objective of 'driving' the strategy.

Again, the intervention of the pandemic has severely limited the range of fundraising initiatives possible. As an example, a major fundraising event involving celebrities, at a well-known national sports location, was planned for later in the year. This, together with many of the external physical events which have been a regular source of income for us, have had to be cancelled.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

However, work continues on identifying virtual fundraising opportunities.

Following a period of improving income streams, a decision was also made to recruit additional staff as employees. The decision was based on several factors. All previous staff members had worked for the Charity on a self-employed basis, which was felt to be detrimental to the commitment, longevity and necessary learning of the individuals concerned. Two new members of staff were subsequently employed as an Office Manager and Administrative Assistant prior to the pandemic. The appointments have enabled us to make improvements in our information technology systems together with improved communication.

The expansion of our locally based support groups continued in the past year with new groups established e.g. in Kent. The pandemic has meant that Support Groups were unable to meet in person and consequently a system of virtual support groups has been devised. To some extent the greater use of meetings via media communication platforms, such as Zoom, have enabled us to expand the types of specific support offered, e.g. for carers and the bereaved, as well as those who had previously been unable to attend local support groups due to their residence in sparsely populated areas where there were no other MDS patients. We continue to explore the formation of additional specialist support groups to enable vital support to be offered during the ongoing lockdown. It must be remembered that Governmental easing of lockdown restrictions has little significance for MDS patients, as they remain at high risk whilst the threat of Covid-19 or Covid derivatives continues and consequently virtual meetings remain our primary method of communication.

The Charity, led by its CEO, has again played a major part in continuing to champion, lead and involve itself in organisations involved in blood cancers and rare cancers both in the United Kingdom and abroad. Our CEO has detailed our involvement in her report. Suffice it to say that MDS UK Patient Support Group continues to 'punch above its weight' both in National and International organisations in which it is involved.

Whilst the Charity has taken major decisions over the past year to expand and diversify, the impact of Covid has severely impacted us, probably to a greater extent than larger charities. As previously indicated, our venture into clinical research, taking on new members of staff as employees and utilising a fundraising specialist company to devise a fundraising strategy has been expensive. Our income has traditionally relied on support from those affected by MDS, who regularly undertook physical challenges throughout the year, as well as pharmaceutical grants. The pandemic has caused almost all planned external activities to be cancelled and we are having to adapt and devise new inventive ways of raising funds. However, despite the downturn in income streams occurring at an inopportune time for us, we have the necessary reserves to enable us to cover the likely deficit for the current year.

Once again, I would like to thank all those associated with MDS UK, including the members of our Board, all volunteers, patients and carers, members of staff and those within the NHS who have assisted us throughout the year and without whom the Charity could not exist.

Edward Peel L LB (Hons)
Chair MDS UK

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

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

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)
- 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
- Providing patient expertise at EMA (European Medicines Agency) level
- 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
- Participation in PPI (Patient and Public Involvement) review work at NCRI level, as well as national care and treatment guidelines for MDS.
- Patient expert and PPI reviews for clinical trials (commercial and institutions)

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.

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

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). This survey is the largest scientifically representative sample of MDS patients in the UK and a proportion of data was analysed and presented. This work has since generated great further interest from other stakeholders, but changes in staffing, as well as the advent of COVID-19, including provisions to work from home, have prevented further work from taking place in this financial year. The remaining data will be analysed end of 2021, COVID-permitting.
- MDS World Awareness Day was marked by a successful campaign involving poetry about MDS, with contributions across the UK and the rest of the world. The MDS World Awareness Day will continue to be marked in the future, in partnership with the international MDS Alliance.
- MDS UK took part in the Make Blood Cancer Visible Campaign, to mark Blood Cancer Awareness Month in September.
- The charity concentrated on strengthening its local patient groups, which often are more convenient for elderly patients to attend. 1 further new group was created, and the potential for 4 new ones. A national patient forum event this year was not possible, due to the need to train new staff, and the advent of COVID-19. Several local meetings had to be cancelled due to COVID-19. In March 2020, MDS UK started exploring ways to implement virtual patient meetings for our members.
- 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 start of the 3rd edition of the MDS Patient Handbook (in collaboration with Leukaemia CARE and Bloodwise) was postponed due to COVID-19.
- Two editions of an extended version of the MDS UK Newsletter were published, in June 2019 and March 2020, with a new Newsletter editor.
- The choice of the PhD topic was completed, with assistance of the scientific advisory board. A candidate was identified and started work – but progress was interrupted by COVID-19.
- In terms of clinical trials, MDS UK has maintained and further strengthened the level of PPI (Patient and Public Involvement) work with the NCRI MDS group of experts. A unique model of partnership was co-developed, enabling a much broader participation of patients to provide their perspectives and opinions about a new university led feasibility

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

trial. This model of cooperation will be recommended as a future best practice model for PPI.

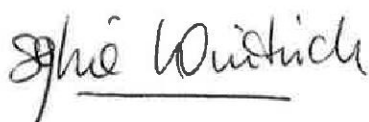
- MDS UK has completed the PPI review for the latest update for the National BSH (British Society of Haematology) Treatment Guidelines for MDS.
- MDS UK participated in further commercial trial reviews and research projects for pharmaceutical companies, from a PPI perspective.
- MDS UK submitted evidence for a NICE HTA in January 2020 for a new MDS drug. The HTA was subsequently cancelled, with no new date announced so far. MDS UK has been actively pursuing discussions regarding compassionate use or early access to this new drug.
- 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. Pharmaceutical companies have also been glad to see trial information being provided, due to slow or difficult recruitment circumstances.
- 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 coming to the end of its 2-year chairmanship in December 2019. MDS UK continues to lead several working groups within MDS Alliance.
- 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. However, COVID-19 has significantly slowed down progress with this project.
- 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 staffing, MDS UK revised the office set-up, by directly employing personnel through PAYE. The Office Manager position has been maintained, and a dedicated Membership Officer role was created to streamline processes, due to an increased level

Report of the Trustees for the year ended 31st March 2021

of activities and membership level. A full-time Fundraising Officer staff member was appointed, taking over from a previous part-time volunteer. Significant training time was dedicated to new staff in early 2020.

HR tasks were allocated to a committee member for the time being.

- A Fundraising Strategy was developed further, to ensure longer term sustainability of the charity and its services, however, plans and progress had to be revised due to COVID-19.
- Significant revisions to the IT and database setup were implemented in late 2019, to improve work processes. However, COVID-19 forced a complete change of work practices and hardware, by having to operate remotely, as staff needed to work from home. A new IT support company was appointed for this process.
- COVID-19 significantly interfered with the end of the financial year, doubling the amount of helpline and email workload. The pandemic also forced a complete overhaul of working practices, job descriptions, and re-training of existing and new staff, to respond to the need and demand for new services being accessible virtually and remotely.
- The Charity changed from a company limited by guarantee to a charitable incorporated organisation (CIO). For many years charities in England and Wales have had to make do with legal structures that were originally intended for other purposes, such as trusts and limited companies. The legal framework within which companies operate was never intended for charitable organisations, and there is a constant tension between the regulations which charities face under the Charities Acts and the obligations which are imposed on companies by company law. The CIO is intended to provide charities with the benefits of incorporation to registered charities within a more attractive legal framework that is regulated purely by the Charities Commission. By adopting the CIO we have simplified our regulation and reporting requirements and have taken the opportunity to adopt a new constitution and code of conduct more appropriate to the charity we operate today.



Sophie Wintrich
Chief Executive

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

Financial Review

The following figures were taken from the full accounts approved on 29th October 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 - £180,512. Money spent - £155,999

Overall, we ended with a surplus of £24,513 compared to a deficit of £215,362 in 2019/20.

Money received: sources of funds

Total income for the year of £180,512 was 92% higher than the previous year (2019/20)- £93,977) Donations of £148,298 from members of the public and relatives of patients were greater than last year thanks partly to the 20-20 fundraising campaign. We were fortunate to receive £15,151 income from legacies, (2019/20 £0). A grant of £10,000 was received from Janssen and £750 from Novartis. Both were unrestricted and complied with the Code of Practice for the UK Pharmaceutical Industry.

Money spent:

Expenditure for the year of £155,999 was £153,340 less than last year which included a provision of £173,046 for the research grant. Covid has affected the amount of face to face activities replaced by Zoom sessions at a significantly lower cost. There was an increase in staff costs as seconded or contract staff were replaced by our own employees.

The surplus for the year of £24,513 has been added to unrestricted reserves which now amount to £189,937.

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 impact of COVID-19 on the ability of the charity to raise funds and the increase in demand for our services. The trustees have considered continued uncertainty due to Covid 19, the level of funds held, and the expected level of income and expenditure for the 12 months following the approval of these financial statements. They have concluded that the budgeted income and expenditure with the existing level of free reserves is sufficient for the Charity to be able to continue as a going concern

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

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

Trustees

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

Edward Peel
Sophie Wintrich
Fiona Pirilla (resigned 21st May, 2021)
Don Barrett
Russell Cook
Chris Charlwood
Claudia Richards
Tony Allen (appointed 1st October, 2021)
Lin Holder (appointed 1st October, 2021)

Key management personnel:

Chief Executive: Sophie Wintrich

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

Structure, Governance and Management

Governing document

As explained in the Chief Executive's Report 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. There is also a management committee of all the members of the CIO which meets quarterly. A Chief Executive is appointed by the trustees.

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.

This is an especially important exercise at the current time in view of the risks surrounding COVID-19. The principal risk is that the impact on fundraising could reduce the level of activities undertaken by the charity.

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

MDS UK PATIENT SUPPORT GROUP

Report of the Trustees for the year ended 31st March 2021

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



Edward Peel (Chair)

Date

Unaudited Statement of Financial Activities (Incorporating Income and Expenditure Account) for the year ended 31st March, 2021.

		2021	2020
		£	£
	Note	Total	Total
Income from			
Donations and similar incoming resources	3	148,298	82,202
Legacies	3	15,151	-
Grants	4	10,750	6,500
Investment income	5	1,104	1,766
Other Income		5,209	3,509
Total income		180,512	93,977
Expenditure on			
Raising Funds	6	3,952	17,861
Charitable activities	7	152,047	116,927
Provision for Research grant	9	-	173,046
Governance Costs	11	-	1505
Total expenditure		155,999	309,339
Net income		24,513	-215,362
Reconciliation of funds			
Total funds brought forward		165,424	380,786
Total funds carried forward		189,937	165,424

All amounts relate to continuing activities

The notes on pages 15 to 18 form part of these financial statements

Unaudited Balance sheet
As at 31st March 2021.

		2021	2020
		£	£
	Note	Total	Total
Current assets:			
Debtors	13	7,199	4,710
Current asset investments	14	298,526	322,423
Cash at bank and in hand		42,835	34,385
Liabilities: Amounts falling due within one year			
Creditors and accruals	15	-15,091	-26,800
Total Net Assets		333,469	334,718
Provision for research grant		143,532	169,294
The Funds of the Charity		189,937	165,424
Unrestricted income funds	16	189,937	165,424
Total funds		189,937	165,424

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 13 to 18 were approved by the board of trustees on the 19th November, 2021 and authorised for issue and signed on its behalf by:

E Peel
Chair

Registered Charity Number: 1145214

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 to respond to Covid 19. We expect to incur a surplus for the year ending 31 March 2022 as we have been informed of a considerable legacy the exact amount of which is yet to be finalised. Any surplus reserves will be designated to promote and support scientific research into MDS

Cash flow Statement

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

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 budgeted income and expenditure is sufficient with the unrestricted reserves of £189,937 for the charity to continue as a going concern.

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.

Unaudited notes to the financial statements as at 31st March 2021

2) Trustees' Remuneration

The charity reimbursed Kings College Hospital Trust for emoluments of £34,913 and pension and NI contributions of £8,648 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.

	2021 £	2020 £
Donations (including Gift Aid)	148,298	82,202
Legacies	15,151	-
	<u>163,449</u>	<u>82,202</u>

4) Grants

Novartis	750	-
Janssen	10,000	6,500
	<u>10,750</u>	<u>6,500</u>

5) Investment Income

Bank Interest Received	<u>1,104</u>	<u>1,766</u>
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6) Costs of raising funds

Advertising and promotion	1,070	4,809
Consultant	2,260	8,432
Event Costs	622	4,620
	<u>3,952</u>	<u>17,861</u>

7) Costs of activities for charitable objectives

Reimbursed staff costs (2 secondees)	44,658	43,561
Staff costs	66,974	-
Consultant	-	1,250
Donor database development/maintenance	2,760	1,650
Website	11,765	10,540
Newsletters	-	26,893
Literature and Information Sheets	3,066	1,262
Myelo's Hope MDS Animation	14,975	-
National Forums	-	-
Local Support Groups	14	1746
Survey	853	-
Conference Participation	-	1,717
Travel and expenses	13	355
Support costs (Note 10)	6,969	27,953
	<u>152,047</u>	<u>116,927</u>

Unaudited notes to the financial statements as at 31st March 2021

8) Staff Costs and Emoluments

	2021	2020
	£	£
Salaries	60,380	11,329
Social security costs	4,940	868
Pension costs	1,654	283
	<u>66,974</u>	<u>12,480</u>

9) 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 total of £25,761 was reimbursed during the year. A provision for the full amount of the grant was made in the previous year in accordance with the Charities SORP (FRS 102)

	2021	2020
	£	£
Support Staff	-	12,480
Contract staff	-	9,740
Payroll costs	616	-
Stationery and postage	251	1,034
Telephone and broadband	1,128	1,158
Office computer and software	3,377	2,050
Recruitment	-	777
Sundry expenses	1,597	714
	<u>6,969</u>	<u>27,953</u>

11) Governance costs

AGM & governance meetings	-	1,505
	<u>0</u>	<u>1,505</u>

12) Taxation

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

13) Debtors

Gift Aid Recoverable	5,729	1,815
Prepayments	1,350	2,700
Other	120	195
	<u>7,199</u>	<u>4,710</u>

14) Current asset investments

Nationwide Building Society Deposit	75,958	75,871
CCLA Charities Deposit	48,609	83,526
Co-Op Instant Access	65	64
Hampshire Trust	87,939	87,091
Redwood Bank Deposit	10,000	-
Scottish Widows Deposit	75,955	75,871
	<u>298,526</u>	<u>322,423</u>

15) Creditors

Paye	325	151
Accruals	14,766	26,649
	<u>15,091</u>	<u>26,800</u>

16) Funds

Unrestricted funds of £189,937

Designated	-	-
Undesignated	189,937	165,424
	<u>189,937</u>	<u>165,424</u>

MDS UK PATIENT SUPPORT GROUP

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

I report to the charity's trustees on my examination of the accounts of the charity for the year ended 31 March 2021.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

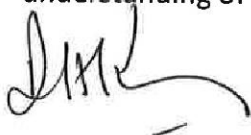
I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

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

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.



D H King BSc FCA
Chartered Accountant
The Dell,
Old Farm Road
Hampton, Middlesex, TW12 3RJ

25 November 2021