

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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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;

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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,

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

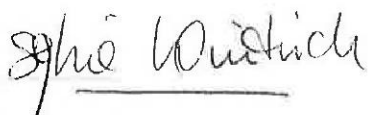
continuing to provide support to patients and full participation in clinical work, all through the pandemic, and the personnel were thanked for their efforts in this regard. Although most Covid-19 related workplace restrictions had eased, it was agreed to continue with on-line meetings given the vulnerability 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

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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.

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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.

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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').

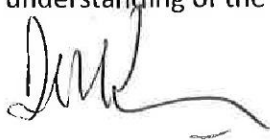
I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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