

REGISTERED COMPANY NUMBER: 07790071 (England and Wales)
REGISTERED CHARITY NUMBER: 1144342

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024

FOR

NARCOLEPSY UK

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FOR THE YEAR ENDED 31 DECEMBER 2024

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

The trustees present their report and accounts for the year ended 31st December 2024, which are also prepared to meet the requirements for a Director's report and accounts for Companies House purposes.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

OBJECTIVES AND ACTIVITIES

As set out in its Articles of Association, the objectives of Narcolepsy UK are to provide relief and aid to those suffering from Narcolepsy and Idiopathic Hypersomnia. To that end, we support people with Narcolepsy and Idiopathic Hypersomnia, their families, carers and others interested in improving their quality of life.

Our principal activities to achieve these objectives are:

- The promotion and/or assistance in promoting and carrying out research, surveys and investigations into narcolepsy and its effects.
- Supporting affected people with advice and information
- The promotion and organisation of conferences relating to narcolepsy and its effects.
- Creating and funding strategies that make this work possible.
- Arranging and providing exhibitions, meetings, lectures, classes and training courses.
- Collecting and distributing information, primarily through the Narcolepsy UK media portfolio comprising website, Facebook, Twitter and social media generally.

Narcolepsy UK's achievements in relation to these objectives are summarised below under the heading Achievements and Performance.

Our vision is to help provide a world where narcolepsy is understood and people with narcolepsy have the support they need to ensure that their rights are upheld and that they have the same opportunities as others in society.

We will deliver our objectives by:

- Raising professional, political and public awareness and understanding of the needs of people with narcolepsy, their families and carers.
- Campaigning to influence the policies of legislators and funding bodies.
- Delivering relevant sustainable services that satisfy the needs of people with narcolepsy, their families and carers.
- Providing information and practical support to people with narcolepsy, their families and carers, either directly, in partnership with others or through facilitating and supporting the work of other organisations.
- Supporting research into the effects and management of narcolepsy.

We seek to work in partnership with those who share our vision and mission.

Our strategic aim is to achieve all this through a combination of fundraising, continuing dialogue with politicians, medical professionals, industry and similar patient groups throughout the world, across a variety of projects.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

ACHIEVEMENT AND PERFORMANCE

Core activities

As planned, all core activity was undertaken under the umbrella of the Narcolepsy Charter and focused on direct, interventional support across education, work, family and social care

We remain impacted by the dual impact of Brexit and post-Covid economics in that we have seen our funding, whether from individual or group sponsored events, decrease at the same time as we have seen some of our corporate supporters actively move away from both operational and new development activity in the UK, in favour of the larger market in the USA with its potentially speedier route to approval provided in the USA by the Federal Drug Administration.

It is becoming increasingly difficult to offset this against demand where requests for help via our Helpline grew during the past 12 months. We supported 140 new Personal Independence Applications, 10 Universal Credit applications and 9 New Disability Living Allowance applications (DLA relates to children only).

These numbers exclude any appeals, tribunals, and assistance of any other nature.

Our Benefits Officer assisted both adults & children in making successful claims totalling £1.3m for Disability Living Allowance & Personal Independence Payments. Some awards may have been applied for prior to that year but the final decision on those awards was made in 2023. All award decisions included in the total of £1.3m were made in 2024.

Our registered membership increased from 3452 to 3698 over the year. Narcolepsy is a rare condition, taking several years for people to reach the diagnosis stage at which time consultants frequently recommend them to contact Narcolepsy UK for more information about living with the disability and provision of help with social care, benefits, workplace adjustments, support in education (infant to university), housing and many other aspects of life.

During 2024 we actively assisted 34 people to obtain diagnosis by asking their GP to make a referral to a Sleep Centre, others may have decided to follow this course of action individually by using the relevant information on our website

Total Voluntary hours 1054.50

Total Voluntary Value of these hours £17340

This past year has seen a growth in volunteers working on social media projects, increasing our multi-channel presence to further raise awareness of the condition and the free services that Narcolepsy UK provide.

External Engagement

We maintained our relationships with existing pharmaceutical companies active in the field of Narcolepsy and Idiopathic Hypersomnia treatments and actively developed new connections with recent entrants to the market. In line with our charitable aims, we have also undertaken in-person staff awareness training with some of these organisations.

One of our critical activities is providing the patient perspective of the condition from a personal, medical interaction & general social perspective for both current and future sleep clinicians. In doing this, we have maintained our relationship with Warwick Medical School by presenting on living with Narcolepsy to their medical students as part of their annual Sleep Health and Society module.

We also presented to students on the NHS England National School of Healthcare Science STP (Scientist Training Programme), a masters level programme providing clinical scientists in the areas of respiratory & sleep sciences, some of whom will work with patients.

We attended a lived experience and peer support day at University of the West of England in Bristol. The aim of the day was to provide students with insights from patients about their lived experience of sleep disorders and highlight sources of peer support which they can signpost for their patients.

We also presented at the on-site culmination of the Online Programme in Sleep Medicine which leads to a PGDip or MSc. It is hosted by the Sleep and Circadian Neuroscience Institute (SCNi) which sits within the Nuffield Department of Clinical Neurosciences at the University of Oxford. The SCNi brings together world leading expertise in basic and human sleep and circadian research, and in the evaluation and management of sleep disorders.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

All of the above engagements resulted in excellent feedback on our presentations, evidenced by our being requested to repeat sessions for 2025.

We continued to work closely with the UK Driver and Vehicle Licensing Agency on both policy and specific individual driver issues and this relationship has proved to be very successful when we have been asked to intercede in the licensing process by an individual with Narcolepsy or Idiopathic Hypersomnia. We are regular attendees at the DVLA Charity Forum and in 2024 we contributed to the Department of Transport call for evidence for driver licensing for people with medical conditions. Our contribution is noted in the formal review report dated 7th November 2024.

Anticipated Next Steps

We have seen what we expected to be a temporary decrease in the activity of pharmaceutical developments for Narcolepsy and Idiopathic Hypersomnia for the UK market as new formulations are following research & clinical trials primarily based in the USA.

This does place us at a disadvantage but it is one we are fully aware of and have taken steps to ensure that we will be able to run our services to cover increased need whilst ensuring that our costs are kept to an absolute minimum.

FINANCIAL REVIEW

Financial Review and Results for the year

The Statement of Financial Activity reflects all incoming resources receivable in the period irrespective of when the income is spent. The Trustees are satisfied with the results for the period.

Reserves policy and going concern

Free reserves available for use by Narcolepsy UK are deemed to be those that are readily realisable, less funds whose uses are restricted or designated for particular purposes.

We aim to hold an operational reserve of liquid assets (cash or near cash), the total of which should equate to at least six months' cash flow. However, this is not always possible and requires careful management of available funds during critical periods whilst sourcing new income streams.

We forecast that 2025 will be a financially difficult year but one where we anticipate to retain general donations from friends of the charity which may not allow growth in staffing or expenditure but will maintain our ability to continue to provide our services at no cost.

A new website has been created during 2024 (the result of a generous donation). The website does provide a dedicated option to donate to the charity on a one-off or regular basis for those who can afford it.

With income, the major risk is of a decline in income particularly due to economic or other factors leading to both declining legacy values and reduced donations. This is something which has been and will continue to be addressed daily. Alongside this more project related funding will be sourced.

The Trustees have reviewed the circumstances of Narcolepsy UK and consider that adequate resources will continue to be available to fund the activities of the charity in the medium term. The trustees are of the view the charity is a going concern (albeit needing constant review).

During 2024 our Trustees Henry Nicholls and Michael Guthrie retired from the board. We thank them for their service.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

07790071 (England and Wales)

Registered Charity number

1144342

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2024

Registered office

Yew Tree House
The Shrubbery
Church Street
St Neots
Cambridgeshire
PE19 2BU

Trustees

T J Kavanagh
E H Nicholls (resigned 11.4.24)
M M O'Neill Chair
Dr H Strongman
D G Brocksom
M J J Guthrie (resigned 31.8.24)

Company Secretary

Mrs N S Rule

Independent Examiner

Bradshaw Johnson
Chartered Accountants
Croft Chambers
11 Bancroft
Hitchin
Hertfordshire
SG5 1JQ

Approved by order of the board of trustees on 30 May 2025 and signed on its behalf by:

M M O'Neill - Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
NARCOLEPSY UK

Independent examiner's report to the trustees of Narcolepsy UK ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2024.

Responsibilities and basis of report

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

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

Independent examiner's statement

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

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

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

Neil C Harding FCA

Bradshaw Johnson
Chartered Accountants
Croft Chambers
11 Bancroft
Hitchin
Hertfordshire
SG5 1JQ

Date:

NARCOLEPSY UK

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2024

		Unrestricted fund £	Restricted fund £	31.12.24 Total funds £	31.12.23 Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	55,087	7,875	62,962	50,290
Investment income	4	770	-	770	468
Total		<u>55,857</u>	<u>7,875</u>	<u>63,732</u>	<u>50,758</u>
EXPENDITURE ON					
Charitable activities					
Narcolepsy UK		<u>54,211</u>	<u>7,875</u>	<u>62,086</u>	<u>62,811</u>
NET INCOME/(EXPENDITURE)		1,646	-	1,646	(12,053)
Transfers between funds	12	<u>5,000</u>	<u>(5,000)</u>	<u>-</u>	<u>-</u>
Net movement in funds		6,646	(5,000)	1,646	(12,053)
RECONCILIATION OF FUNDS					
Total funds brought forward		37,820	6,968	44,788	56,841
TOTAL FUNDS CARRIED FORWARD		<u><u>44,466</u></u>	<u><u>1,968</u></u>	<u><u>46,434</u></u>	<u><u>44,788</u></u>

The notes form part of these financial statements

STATEMENT OF FINANCIAL POSITION
31 DECEMBER 2024

	Notes	Unrestricted fund £	Restricted fund £	31.12.24 Total funds £	31.12.23 Total funds £
FIXED ASSETS					
Tangible assets	9	4	-	4	196
CURRENT ASSETS					
Debtors	10	2,767	-	2,767	1,361
Cash at bank		43,393	1,968	45,361	44,678
		<u>46,160</u>	<u>1,968</u>	<u>48,128</u>	<u>46,039</u>
CREDITORS					
Amounts falling due within one year	11	(1,698)	-	(1,698)	(1,447)
NET CURRENT ASSETS		<u>44,462</u>	<u>1,968</u>	<u>46,430</u>	<u>44,592</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>44,466</u>	<u>1,968</u>	<u>46,434</u>	<u>44,788</u>
NET ASSETS		<u>44,466</u>	<u>1,968</u>	<u>46,434</u>	<u>44,788</u>
FUNDS	12				
Unrestricted funds				44,466	37,820
Restricted funds				<u>1,968</u>	<u>6,968</u>
TOTAL FUNDS				<u>46,434</u>	<u>44,788</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2024 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 30 May 2025 and were signed on its behalf by:

M M O'Neill - Trustee

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024

1. STATEMENT OF COMPLIANCE

Narcolepsy UK is a charitable company incorporated in England. The registered office is :

Yew Tree House
The Shrubbery
Church Street
St Neots
Cambridgeshire
PE19 2BU

The charitable company's financial statements have been prepared in compliance with Charities SORP (FRS 102) as it applies to the financial statements for the year ended 31 December 2024.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Narcolepsy UK meets the definition of a public benefit entity under FRS 102.

The financial statements are presented in sterling (£).

Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution.

Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

Expenditure and irrecoverable vat

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classified under the following activity headings:

- Costs of raising funds comprise the costs of their associated support costs.
- Expenditure on charitable activities includes the costs of conferences and fundraising and their associated support costs.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2024

2. ACCOUNTING POLICIES - continued

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pensions

During the year, the charitable company operated a pension scheme with B&CE Holdings Ltd. Contributions payable for the year are charged in the profit and loss account.

Legal status of the charitable company

In the event of the charitable company being wound up, each Trustee (being a member of the charity) has undertaken to contribute to the assets of the charitable company such amounts as required not exceeding £1. This guarantee extends until one year after a Trustee ceases to be a member. The Trustees control the charitable company.

Debtors and prepayments

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Financial instruments

The charitable company only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

NARCOLEPSY UK

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2024

3. DONATIONS AND LEGACIES

	31.12.24	31.12.23
	£	£
Donations	55,087	40,450
Grants	7,875	9,840
	<u>62,962</u>	<u>50,290</u>

Grants received, included in the above, are as follows:

	31.12.24	31.12.23
	£	£
Other grants	7,875	9,840
	<u>7,875</u>	<u>9,840</u>

4. INVESTMENT INCOME

	31.12.24	31.12.23
	£	£
Bank interest	770	468
	<u>770</u>	<u>468</u>

5. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	31.12.24	31.12.23
	£	£
Depreciation - owned assets	192	639
	<u>192</u>	<u>639</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2024 nor for the year ended 31 December 2023.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 December 2024 nor for the year ended 31 December 2023.

7. STAFF COST

The average monthly number of employees during the year was as follows:

	31.12.24	31.12.23
	3	3
Staff	<u>3</u>	<u>3</u>

No employees received emoluments in excess of £60,000.

NARCOLEPSY UK

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2024

8. 2023 COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted fund £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	40,450	9,840	50,290
Investment income	468	-	468
Total	<u>40,918</u>	<u>9,840</u>	<u>50,758</u>
 EXPENDITURE ON			
Charitable activities			
Narcolepsy UK	<u>54,939</u>	<u>7,872</u>	<u>62,811</u>
 NET INCOME/(EXPENDITURE)	 (14,021)	 1,968	 (12,053)
 RECONCILIATION OF FUNDS			
Total funds brought forward	51,841	5,000	56,841
 TOTAL FUNDS CARRIED FORWARD	 <u>37,820</u>	 <u>6,968</u>	 <u>44,788</u>

9. TANGIBLE FIXED ASSETS

	Computer equipment £
COST	
At 1 January 2024 and 31 December 2024	<u>1,960</u>
 DEPRECIATION	
At 1 January 2024	1,764
Charge for year	<u>192</u>
At 31 December 2024	<u>1,956</u>
 NET BOOK VALUE	
At 31 December 2024	<u>4</u>
At 31 December 2023	<u>196</u>

NARCOLEPSY UK

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2024

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.24	31.12.23
	£	£
Prepayments	2,767	1,361
	<u>2,767</u>	<u>1,361</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.24	31.12.23
	£	£
Other creditors	1,698	1,447
	<u>1,698</u>	<u>1,447</u>

12. MOVEMENT IN FUNDS

	At 1.1.24 £	Net movement in funds £	Transfers between funds £	At 31.12.24 £
Unrestricted funds				
General fund	37,820	1,646	5,000	44,466
Restricted funds				
Regional Support and other restricted funds	6,968	-	(5,000)	1,968
TOTAL FUNDS	<u>44,788</u>	<u>1,646</u>	<u>-</u>	<u>46,434</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	55,857	(54,211)	1,646
Restricted funds			
Regional Support and other restricted funds	7,875	(7,875)	-
TOTAL FUNDS	<u>63,732</u>	<u>(62,086)</u>	<u>1,646</u>

Comparatives for movement in funds

	At 1.1.23 £	Net movement in funds £	At 31.12.23 £
Unrestricted funds			
General fund	51,841	(14,021)	37,820
Restricted funds			
Regional Support and other restricted funds	5,000	1,968	6,968
TOTAL FUNDS	<u>56,841</u>	<u>(12,053)</u>	<u>44,788</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2024

12. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	40,918	(54,939)	(14,021)
Restricted funds			
Regional Support and other restricted funds	9,840	(7,872)	1,968
TOTAL FUNDS	<u>50,758</u>	<u>(62,811)</u>	<u>(12,053)</u>

13. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2024.

14. NAMES AND PURPOSE OF FUNDS

Unrestricted funds

General

This fund reflects the accumulated surplus arising from the general activity of the charity after allocating income and expenditure to other funds where appropriate and consistent with policy of the charity.

Restricted funds

Regional Support and other restricted funds

These funds have been donated specifically to allow the charity to provide support and information services within a particular region or for other particular or restricted purposes, both through enabling the creation and development of local volunteer/supporter sub groups which are better able to focus on local needs and through the provision of a local and regional support infrastructure to ensure that such groups operate efficiently and effectively in a co-ordinated manner to the highest standards.