

Charity registration number 1106008 (England and Wales)

Charity registration number SC051539 (Scotland)

Company registration number 05142341 (England and Wales)

ALEX, THE LEUKODYSTROPHY CHARITY
ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

ALEX, THE LEUKODYSTROPHY CHARITY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	L Milne	
	O Bostock	
	G Metcalf	
	J Livingston	
	I Idafar	
	E Hadfield-Hudson	
	K Amber	(Appointed 9 August 2023)
	T Sandys-Winsch	(Appointed 11 October 2023)
	G Sarig	(Appointed 4 January 2024)
	T Dalton	(Appointed 12 May 2024)
Secretary	N Shiroi	(Appointed 16 April 2024)
	S Tan	(Appointed 2 May 2024)
	S Baldini	(Appointed 6 September 2024)
Charity number (England and Wales)	1106008	
Charity number (Scotland)	SCO51539	
Company number	05142341	
Registered office	45 Peckham High Street	
	London	
	SE15 5EB	
Auditor	Richard Place Dobson Services Limited	
	Ground Floor	
	1 - 7 Station Road	
	Crawley	
	West Sussex	
	RH10 1HT	

ALEX, THE LEUKODYSTROPHY CHARITY

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ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 30 JUNE 2024

The trustees present their annual report and financial statements for the year ended 30 June 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) 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 2019)".

Objectives and activities

The charity's objects are:

- the relief of sickness of people with leukodystrophy (also known as Inherited White Matter Disorders) and their parents and carers;
- to promote medical research into leukodystrophy and the publication of useful results of such research for the benefit of the public; and
- to advance the education of the public in leukodystrophy.

Achievements and performance

Organisation

For this period, Alex TLC focussed on sustainability after a period of rapid growth, ensuring maintenance of service levels, project completions and nurturing stakeholder relationships.

During the period we evidenced improved visibility of Alex TLC and welcomed 157 new beneficiaries (a 30% increase year on year) increasing the number of conditions represented to 23, and delivered 2,196 support activities to 748 beneficiaries. Connecting beneficiaries with each other for mutual support is one of our key objectives and we successfully encouraged 78 new relationships, a 39% improvement year on year.

Our direct communication with the community has seen consistent improvement, and whilst our newsletter open rate dropped by 2% to 39%, our research summary open rate increased from 33% to 41%. Subscriptions to our newsletter also grew from 55 to 447 over the reporting period, largely due to review and adaptation of our subscription process. Communications and engagement staff developed their social media skills utilising training and consultancy opportunities, growing engagement across all social media channels over the year by 78%.

We restructured our Impact Reporting following feedback from our 2022 Impact Report on the length of the survey, which covered respondent demographics, views on available services as well as all areas of our work. As a result, we moved questions related to our support services including our counselling and peer support services, to a separate survey, and shared with all community members who have accessed these. Our first Support Services Impact Report was published in April 2024, and demonstrated how highly valued our support services are:

- "when I need support I know I just have to pick up the phone".
- "...answered my questions with genuine compassion and offered suggestions that proved to be both helpful and comforting."
- "really helped me cope with what I was feeling"
- "always great to speak to others that truly understand this situation"

We also shared our streamlined 2024 Impact Survey and will publish the results towards the end of 2024.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 30 JUNE 2024*

We launched a new website in April 2024, designed to improve user journeys and search engine optimisation, resulting in a 19% rise in visits compared to last year. The new website includes redesigned individual leukodystrophy condition pages, which has resulted in a 50% increase in visits to these pages, which are endorsed by NHS leukodystrophy specialists. They are also used by the NHS England Inherited White Matter Disorder Service (NHSE IWMD Service) as a reference point for patients. We also created a new suite of comprehensive pages to help users understand research development, an individual condition search facility for our research summaries, and regularly updated clinical trial information.

September 2023 was Leukodystrophy Awareness Month and we launched a new campaign to “Light up Blue” (the brand colour for leukodystrophy). Across the UK a total of 43 buildings lit up blue and our social media engagement more than doubled during the month using a comprehensive schedule of engaging and interactive activities.

During the year promising results were seen in clinical trials for Leriglitazone, a drug which may protect patients against the neurodegenerative effects of adrenoleukodystrophy (ALD). We submitted a report as evidence to demonstrate the positive impact of the drug and were asked to represent patient voice in meetings to assess a licencing application with the European Medicines Association. Unfortunately, this was unsuccessful but has created an opportunity to reapply once further investigations have been completed.

We were also asked to represent the patient voice by NHS England Specialised Commissioning and were able to advocate successfully to remove the age limit on the NHS policy for bone marrow transplants in the treatment of cerebral ALD, ensuring access to this life-saving procedure for adults as well as children.

We also worked successfully with Genetic Alliance on an application to include Aicardi-Goutières Syndrome 8 on the Human Fertilisation and Embryology Authority approved condition list for pre-implantation genetic testing. This provides carriers of the condition the option to undergo fertility treatment in order to have children unaffected by the condition.

The period focussed on stability and sustainability, and we undertook several measures to upskill staff and improve infrastructure and internal processes including:

- Time management training
- Management training for retail managers
- Plain English training for support, research, and communications staff
- A new cloud-based server
- Completion of Cyber Essentials certification
- Additional key performance indicators for improved analysis of diversity and support work
- New strategy development process for support services, communications and fundraising
- A new accountancy firm for production of our management accounts and budget
- A new HR firm and dedicated project to improve retail performance

The retail business continued to improve and the overall contribution from our five charity shops was £81,735 (2022/3: £77,399), a 6% increase. Donation and fundraising income continued to grow to £118,868 (2022/23: £100,707), an increase of 18%. Grant income was £104,500 (2022/23: £156,755), the reduction due to rescheduling of our annual Community Weekend event to October 2024 which has moved some of our fundraising into the next financial year.

Although the organisation saw a reduction in unrestricted reserves of £30,011 to £204,087, this was expected due to our consolidation strategy for the year and we came in under budget by £12,522.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 30 JUNE 2024

Charitable objectives

Across the year Alex TLC staff:

- welcomed 157 new beneficiaries
- supported 589 beneficiaries across 1,675 support activities including one to one conversations, home visits and advocacy, digital wellbeing sessions and face to face get togethers
- delivered 227 professional counselling sessions and wellbeing calls to 41 beneficiaries
- connected 78 beneficiaries to build supportive, long-lasting relationships
- were invited to present at 18 events including Royal Society of Medicine Gene Therapy Conference, British Paediatric Neurology Association (BPNA) conference, Imperial MSc in Genomic Medicine (a carrier's perspective), Royal College for Paediatric and Child Health/Genomics England (The Generation Study)
- attended 30 stakeholder conferences and events including Rare Disease All Party Parliamentary Group: Access to New Research, NHSE IWMD Service annual meeting, and hosted stands at Society of Endocrinology and BPNA conferences
- been involved in 295 stakeholder meetings including NHSE IWMD Service and Registry development committee, Genetic Alliance Trustee Board, GE Notes, European Reference Network for Rare Neurological Disorders
- encouraged 43,931 engagements on our social media channels
- attracted 38,735 website visitors
- were mentioned in the press 5 times including ITV Anglia news and NHS Executive magazine highlighting the importance of new born screening

We were able to progress several projects during the period which are detailed below:

NHSE IWMD Service and Patient Registry – We continue to lead the patient voice representation in our partnership with this vital leukodystrophy patient service and registry. Support staff and our counsellor met with clinical psychologists to discuss complementary support for the emotional wellbeing of Service patients, and co-developed patient information which is shared during clinic visits, as well as virtual multi-disciplinary meetings with local services. We also worked on the communication strategy for the Service and Registry, a two-pronged approach utilising NHS channels alongside Alex TLC's access to the patient and carer community. Since the IWMD Service mobilised in 2023, Alex TLC have advised 24 patients on referral to the Service via their local consultant. "Alex TLC were pivotal in ensuring we were seeing the correct NHS specialist." Alex TLC Impact Survey 2024.

New Born Screening – As we approach the National Screening Committee's (NSC) second review of ALD new born screening (due late 2024/early 2025), staff represented the patient voice in two significant NSC projects focussing on different aspects of new born screening infrastructure. The study we commissioned with Sheffield Hallam University researchers, "The experiences of parents of children diagnosed with cerebral adrenoleukodystrophy", was published in the journal Child: Care, Health and Development in January 2024, and will be used as evidence. We were also pleased to see ALD and metachromatic leukodystrophy (MLD) included in the Generation Study, a study run by Genomics England to test babies for over 200 treatable genetic conditions at birth, which may influence the long-term future of new born screening in the UK.

Community Weekend – Following the success of and feedback from our April 2023 Community Weekend event, bringing patients, families, medical and research professionals together to learn from and support each other, we decided to move this from a biennial to an annual event. Our 2024 event took place in October in Birmingham and included a dedicated Science Day hosted by our research partner, Leukolabs and NHSE IWMD Service clinical leads.

Challenges

We did not have capacity to progress our plans to cement our position as the umbrella organisation for leukodystrophies in the UK and experienced some challenges in attempts to collaborate with a minority of like-minded groups. Our communications strategy for 2024/25 has been adapted accordingly and we will seek to develop a collaborative relationship with one patient group and use learning from this experience to develop future plans.

It has been challenging to secure the honorary contracts required to allow support staff to attend NHSE IWMD Service clinics, largely due to slow moving bureaucratic obstacles within the host NHS Trusts. This has been partially resolved late in the period.

The value of meeting patients and their families face to face cannot be underestimated; to date we have provided support to 19 new beneficiaries who would not have sought our support otherwise at the ALD clinic at Bristol Children's Hospital and we hope we can mirror this success within the NHSE IWMD Service. This presence is also a key part of our strategy to improve equity, diversity and inclusion across support work.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 30 JUNE 2024*

We were unsuccessful in securing a Grants and Trusts Fundraiser, which impacted our potential for grant fundraising during the period.

Minimum wage increases in April 2024 had a significant impact on our 2024/25 budget and instigated restructuring of salary bands for retail and administration staff.

The Board operated under an interim chair whose term ended in September 2024. Despite a challenging recruitment drive, we were able to appoint a new Chair in time for a seamless transition.

Future Impact

It was gratifying to see the organisation exceeding budget expectations during the period, we have set a break-even budget for the following year to further consolidate our position with a view to future growth.

We have recently recruited a Grants and Trusts Fundraiser and look forward to the results of increased capacity in this area for the next period.

Our contract to provide the distribution service for the Addison's Disease Self Help Group ceased in August 2024, however this will give us additional capacity for small grant fundraising which should mitigate against this income loss.

We will continue to work towards our mission of support and access to treatment for everyone with leukodystrophy.

Financial review

Income Summary

In the year ending 30 June 2024, our total income, net of trading activities and expenditure (Trading Contribution), was £321,795 (2023: £350,199), with major contributions from donations - 34% (2023: 26%), grants - 32% (2023: 45%), and Contribution from trading activities - 29% (2023: 26%).

Expenditure Summary

Total expenditures for the year amounted to £328,735 (2023: £383,381), primarily allocated to Charitable Activities - 67% (2023: 70%), fundraising expenses - 17% (2023: 17%) and administrative costs - 16% (2023: 13%). The reduction in total expenditure primarily reflects efficiencies and changes in planned activities, such as the Community Weekend.

Financial Position Overview

As of 30 June 2024, our total assets were £397,247 (2023: £337,632), which includes cash reserves of £293,637 (2023: £288,452). Liabilities stood at £143,449 the increase on the previous year is mainly due to creditors outstanding at the year-end relating to the upcoming Community Weekend (2023: £78,995), resulting in net assets of £253,798 (2023: £258,637).

Cash Flow Summary

We maintained a positive cash flow throughout the year, with net cash inflows of £5,185. This has ensured our continued liquidity and financial stability.

Key Points on Budget Performance

We budgeted for income of £413,490, but actual income was £91,695 lower, primarily due to the deferral of the Community Weekend from May 2024 to October 2024 so the funding for this has now fallen in the next financial year. Retail contribution exceeded budget by £12,000. Total expenditure were broadly in line with the budget after removing the costs associated with the Community Weekend. As a result, the deficit for the year was £30,011, which was £12,522 lower than budgeted. Although we anticipated a deficit, we are pleased that this was less than expected.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 30 JUNE 2024*

Reserve Policy

At the balance sheet date, the charity had unrestricted funds of £204,096 (2023: £234,105) and restricted funds of £82,421 (2023: £59,351).

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level the trustees feel are sufficient to cover the running costs of the charity for a period of approximately 3 months (£240,000).

We expected a drop in unrestricted reserves for this period whilst we continued to invest in our charitable activities. We are looking towards a break-even budget for 2024/25, consolidating our position whilst continuing to increase our level of charitable activities.

Future Outlook

Looking ahead, we have budgeted for income of £446,240 for the upcoming year and anticipate an increase in funding through new grant applications, funding for the Community Weekend and an increase in the trading contribution as we look to grow our charitable activities, focusing on sustainability, growth and maximising our impact in the community.

Plans for future periods

Work areas for 2024/25 include:

- Confirmation of a data sharing agreement with NHS England in order to analyse NHSE IWMD Registry data and identify priorities for future projects.
- Regular attendance schedule for NHSE IWMD clinics.
- Commitment to annual Community Weekends (2024 event took place in October in Birmingham).
- Translation of our children's support book "When My Brother Got Ill – A Story of Adrenoleukodystrophy (ALD)" to German, French and Spanish.
- Confirm the topic for an additional children's support book, for publication in 2025/26.
- Completion of succession planning and sustainability measures.
- Strategy to review operations and providers across the organisation.

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.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 30 JUNE 2024*

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

L Milne	
G Bridge	(Resigned 12 May 2024)
O Bostock	
T Watkins	(Resigned 16 September 2024)
S Jimenez	(Resigned 11 February 2024)
G Metcalf	
N Sarig	(Resigned 15 October 2023)
J Livingston	
I Idafar	
E Hadfield-Hudson	
K Amber	(Appointed 9 August 2023)
T Sandys-Winsch	(Appointed 11 October 2023)
G Sarig	(Appointed 4 January 2024)
T Dalton	(Appointed 12 May 2024)
N Shiroi	(Appointed 16 April 2024)
S Tan	(Appointed 2 May 2024)
S Baldini	(Appointed 6 September 2024)

Recruitment and appointment of new trustees

The Charity seeks to appoint trustees who have relevant and often specialist knowledge. This has always included ensuring that those directly affected by the condition are among the trustees. This is complemented by appointing as trustees those with complementary skills, e.g. legal, finance, administration or relevant professional experience and knowledge.

None of the trustees has any beneficial interest in the company. All of the trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

Key management remuneration

Key personnel remuneration is reviewed annually alongside performance appraisals within an agreed pay structure and applied using the same approach to pay and reward as for all employees. Any significant increases are approved by the Board of Trustees and reviewed within the constraints of the budget.

Day to day operations

The trustees delegate control of day-to-day operations to the Chief Executive Officer who provides a quarterly report and key performance indicators at Board Meetings. Senior Management and Team meetings are held monthly to review strategy and projects and discuss new opportunities and challenges, which feed into these reports.

Risk

The trustees have assessed the major risks to which the charity is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

The charity maintains a Risk Register. This is managed by the Trustee Risk Sub-Committee who present priority risks and proposed mitigations at quarterly Board meetings for approval.

This report has been prepared in accordance with the special provisions of part 15 of Companies Act 2006 relating to small companies.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 30 JUNE 2024*

The trustees report was approved by the Board of Trustees.

.....
L Milne
Trustee

.....
I Idafar
Trustee

Date:

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF TRUSTEES RESPONSIBILITIES

FOR THE YEAR ENDED 30 JUNE 2024

The trustees, who are also the directors of Alex, The Leukodystrophy Charity for the purpose of company law, are responsible for preparing the Trustees Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended). 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.

ALEX, THE LEUKODYSTROPHY CHARITY

INDEPENDENT AUDITOR'S REPORT

TO THE TRUSTEES OF ALEX, THE LEUKODYSTROPHY CHARITY

Opinion

We have audited the financial statements of Alex, The Leukodystrophy Charity (the 'charity') for the year ended 30 June 2024 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 30 June 2024 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees report; or
- sufficient and proper accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

ALEX, THE LEUKODYSTROPHY CHARITY

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF ALEX, THE LEUKODYSTROPHY CHARITY

Responsibilities of trustees

As explained more fully in the statement of trustees responsibilities, the trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. The objectives of our audit are to obtain sufficient appropriate audit evidence regarding compliance with laws and regulations that have a direct effect on the determination of material amounts and disclosures in the financial statements, to perform audit procedures to help identify instances of non-compliance with other laws and regulations that may have a material effect on the financial statements, and to respond appropriately to identified or suspected non-compliance with laws and regulations identified during the audit.

In relation to fraud, the objectives of our audit are to identify and assess the risk of material misstatement of the financial statements due to fraud, to obtain sufficient appropriate audit evidence regarding the assessed risks of material misstatements due to fraud through designing and implementing appropriate responses and to respond appropriately to fraud or suspected fraud identified during the audit.

However it is the primary responsibility of management, with the oversight of those charged with governance, to ensure that the entity's operations are conducted in accordance with the provisions of laws and regulations and for the prevention and detection of fraud.

In identifying and assessing the risks of material misstatement in respect of irregularities, including fraud, the audit engagement team made enquiries of management, and those charged with governance, regarding the procedures relating to identifying, evaluating and complying with;

1. laws and regulations and whether they were aware of any instances of non-compliance;
2. detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud;
3. the internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations;

As a result of these procedures we consider the most significant laws and regulations that have a direct impact on the financial statements are FRS 102, General Data Protection Regulations, Companies Act, Charities Act 2011, Charities Statement of Recommended Practice, Charities Accounts (Scotland) Regulations 2006 and employment law and regulations. We performed audit procedures to detect non-compliance, which may have a material impact on the financial statements. These included reviewing financial statement disclosures and evaluating advice received from external advisors. There were no significant laws and regulations we deemed as having an indirect impact on the financial statements.

ALEX, THE LEUKODYSTROPHY CHARITY

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE TRUSTEES OF ALEX, THE LEUKODYSTROPHY CHARITY

The audit engagement team identified the risk of management override of controls as the area where the financial statements were most susceptible to material misstatement due to fraud. Audit procedures performed included but were not limited to testing manual journal entries and other adjustments and evaluating the rationale in relation to any significant, unusual transactions and transactions entered into outside of the normal course of business.

Income recognition was also identified as a significant risk, particularly due to increases in grants, shop income and ADSHG income received. All material grants and donations have been assessed and the amount of income recognised in the year has been evaluated. Samples of donations, grants, shop and other income were reviewed and each type of income was also analytically tested. The systems and controls surrounding income recognition was also assessed and documented in the year.

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with part 4 of the Charities (Accounts and Reports) Regulations 2008 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Richard Place Dobson Services Limited
Chartered Accountants
Statutory Auditor

.....
Ground Floor
1 - 7 Station Road
Crawley
West Sussex
RH10 1HT

Richard Place Dobson Services Limited is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 JUNE 2024

		Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
	Notes						
Income and endowments from:							
Donations and legacies	3	112,445	102,555	215,000	77,997	169,574	247,571
Other trading activities	4	741,849	-	741,849	697,726	-	697,726
Investments	5	3,632	-	3,632	1,537	-	1,537
Other income	6	4,457	280	4,737	2,152	240	2,392
Total income		862,383	102,835	965,218	779,412	169,814	949,226
Expenditure on:							
Raising funds	7	698,956	-	698,956	662,184	-	662,184
Charitable activities	8	193,436	79,765	273,201	133,892	185,736	319,628
Total expenditure		892,392	79,765	972,157	796,076	185,736	981,812
Net income/(expenditure) and movement in funds		(30,009)	23,070	(6,939)	(16,664)	(15,922)	(32,586)
Reconciliation of funds:							
Fund balances at 1 July 2023		234,105	59,351	293,456	250,769	75,273	326,042
Fund balances at 30 June 2024		204,096	82,421	286,517	234,105	59,351	293,456

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006

ALEX, THE LEUKODYSTROPHY CHARITY

BALANCE SHEET

AS AT 30 JUNE 2024

	Notes	2024 £	£	2023 £	£
Fixed assets					
Tangible assets	14		32,719		34,818
Current assets					
Stocks	15	5,038		3,217	
Debtors	16	98,572		45,964	
Cash at bank and in hand		293,637		288,452	
		397,247		337,633	
Creditors: amounts falling due within one year	17	(128,643)		(54,051)	
Net current assets			268,604		283,582
Total assets less current liabilities			301,323		318,400
Creditors: amounts falling due after more than one year	18		(14,806)		(24,944)
Net assets			286,517		293,456
The funds of the charity					
Restricted income funds	21		82,421		59,351
Unrestricted funds	22		204,096		234,105
			286,517		293,456

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 30 June 2024, although an audit has been carried out under section 144 of the Charities Act 2011.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements under the requirements of the Companies Act 2006, for the year in question in accordance with section 476.

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

The financial statements were approved by the trustees on

.....
L Milne
Trustee

.....
I Idafar
Trustee

Company registration number 05142341 (England and Wales)

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 30 JUNE 2024

	Notes	2024 £	£	2023 £	£
Cash flows from operating activities					
Cash generated from operations	26		19,250		12,200
Investing activities					
Purchase of tangible fixed assets		(7,808)		(1,274)	
Investment income received		3,632		1,537	
		<u> </u>		<u> </u>	
Net cash (used in)/generated from investing activities			(4,176)		263
Financing activities					
Repayment of bank loans		(9,889)		(9,645)	
		<u> </u>		<u> </u>	
Net cash used in financing activities			(9,889)		(9,645)
Net increase in cash and cash equivalents			5,185		2,818
Cash and cash equivalents at beginning of year			288,452		285,634
			<u> </u>		<u> </u>
Cash and cash equivalents at end of year			293,637		288,452
			<u> </u>		<u> </u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2024

1 Accounting policies

Charity information

Alex, The Leukodystrophy Charity is a private company limited by guarantee incorporated in England and Wales. The registered office is 45 Peckham High Street, London, SE15 5EB.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's memorandum and articles of association, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "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). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern.

1.3 Charitable funds

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.

1.4 Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donations and similar incoming resources are included in the year in which they are receivable, which is when the charity becomes entitled to the resource.

Grant income is recognised at the point when the charity becomes legally entitled to the income and may be deferred in accordance with the terms of the funders at the time of receipt.

Fundraising income is recognised when the charity becomes legally entitled to the income and the event to which it relates has taken place and includes sales of shop goods and is recognised at the point of sale.

Investment income is recognised as it is received.

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

1 Accounting policies

(Continued)

1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Allocation and apportionment of costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include back office and governance costs which support Beneficiary Services, Awareness and Education, Research. These costs have been allocated and apportioned to the various charitable activities.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Plant and machinery	25% straight line
Fixtures & fittings	Straight line over the length of the lease
Motor vehicles	20% reducing balance

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

1 Accounting policies

(Continued)

1.8 Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Consumables and branded items are distributed for free. These are not written down to a nil net realisable value if they continue to meet the need for which they were purchased and they are not damaged or obsolete.

1.9 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.10 Financial instruments

The charitable company only has financial assets and 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.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are measured at transaction price including transaction costs.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

1.11 Taxation

As a registered charity the company benefits from rate relief and is generally exempt from income tax and corporation tax. The charity is not registered for value added tax.

1.12 Employee benefits

The costs of short-term employee benefits are recognised as a liability and an expense.

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.13 Retirement benefits

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

1.14 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

The main judgement and accounting estimates included in the accounts are:

- Depreciation - Management has made assumptions and estimated depreciation rates in respect of showing a true and fair view of the assets at the balance sheet date.

3 Donations and grants

	Unrestricted funds general 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds general 2023 £	Restricted funds 2023 £	Total 2023 £
Donations and gifts	106,845	3,655	110,500	66,347	22,969	89,316
Grants received	5,600	98,900	104,500	11,650	146,605	158,255
	<u>112,445</u>	<u>102,555</u>	<u>215,000</u>	<u>77,997</u>	<u>169,574</u>	<u>247,571</u>

Grants receivable for core activities

EIG Movement for Good	-	-	-	1,000	-	1,000
Michael Watson Charitable Trust	-	-	-	1,000	-	1,000
Minoryx Therapeutics	-	-	-	-	9,992	9,992
Department for Education	-	-	-	1,500	-	1,500
Making a Locally LMADL	-	-	-	1,500	-	1,500
The AMMCO Charitable Trust	-	-	-	500	-	500
The Ardwick Trust	-	-	-	500	-	500
FB Coales No 4	-	-	-	500	-	500
The Sylvia Aitken Charitable Trust	-	-	-	1,000	-	1,000
The Aubrey Orchard Grant	-	1,000	1,000	-	-	-
The Anthony and Elizabeth Mellows Charitable Trust	-	-	-	2,500	-	2,500
London Catalyst Partners for Health	-	-	-	-	2,000	2,000
The Grace Trust	-	-	-	750	-	750
The National Lottery Community Funds	-	34,150	34,150	-	35,660	35,660
The Hospital Saturday Fund	-	-	-	-	2,000	2,000
Affinia Therapeutics	-	-	-	-	1,000	1,000

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

3 Donations and grants

(Continued)

Stagecoach Charity	-	1,000	1,000	-	-	-
CAF The Rest-Harrow Trust	-	-	-	200	-	200
Ionis Pharmaceuticals	-	10,000	10,000	-	20,661	20,661
The P F Charitable Trust	-	2,000	2,000	-	-	-
Orchard Therapeutics	-	-	-	-	7,500	7,500
Garfield Weston Foundation	-	20,000	20,000	-	-	-
Poxel	-	-	-	-	1,000	1,000
Spur Therapeutics	-	5,000	5,000	-	5,000	5,000
R G Hills Charitable Trust	2,000	-	2,000	-	-	-
The Openwork Foundation	-	15,000	15,000	-	-	-
Vigil Neuroscience	-	10,000	10,000	-	11,816	11,816
The Stockwell Cliffe Charitable Trust	600	-	600	-	-	-
Lillie C Johnson Trust	500	-	500	-	-	-
Marsh Christian Trust	750	-	750	700	-	700
The Michael and Anna Wix Charitable Trust	500	-	500	-	-	-
The Tilehouse Trust	-	-	-	-	1,000	1,000
The British Trust for the Myelin Project	-	-	-	-	2,500	2,500
The Gisela Granham Foundation	-	-	-	-	2,000	2,000
Neuraxpharm UK	-	-	-	-	5,000	5,000
Jeans 4 Genes	-	750	750	-	3,000	3,000
Viking Therapeutics	-	-	-	-	10,000	10,000
The Elsie Davis Trust	-	-	-	-	5,000	5,000
Forge Biologics	-	-	-	-	1,488	1,488
BridgeBio	-	-	-	-	4,988	4,988
BBC Children in Need	-	-	-	-	15,000	15,000
JG Akyta Systems Ltd	500	-	500	-	-	-
Other	750	-	750	-	-	-
	<u>5,600</u>	<u>98,900</u>	<u>104,500</u>	<u>11,650</u>	<u>146,605</u>	<u>158,255</u>

4 Other trading activities

	Unrestricted funds general 2024 £	Unrestricted funds general 2023 £
Fundraising income	24,886	28,135
Shop income	716,963	668,506
Shop income - government grants	-	1,085
Other trading activities	<u>741,849</u>	<u>697,726</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

5 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest receivable	3,632	1,537

6 Other income

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Other income	4,457	280	4,737	2,152	240	2,392

7 Expenditure on raising funds

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Fundraising and publicity		
Other fundraising costs	12,618	14,317
Staff costs	42,916	48,837
	55,534	63,154
Fundraising trading:		
Operating charity shops	206,794	190,355
Other trading activities	7,677	6,837
Staff costs	420,008	392,777
Depreciation and impairment	8,943	9,061
	643,422	599,030
Total costs	698,956	662,184

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

8 Expenditure on charitable activities

	Support Services	Awareness and Education	Research	Community Weekend	Total
	2024	2024	2024	2024	2024
	£	£	£	£	£
Direct costs					
Staff costs	68,150	53,830	33,705	-	155,685
Rates and water	1,576	1,576	-	-	3,152
Insurance	260	260	1,442	-	1,962
Light and heat	106	106	39	-	251
Telephone	203	143	15	-	361
Postage and stationery	1,046	40	1,161	-	2,247
Advertising	-	1,444	-	-	1,444
Community Weekend	-	-	-	30,405	30,405
Consultancy fees	-	333	-	-	333
Conference costs	-	2,034	-	-	2,034
Travel costs	1,474	-	-	-	1,474
Subscriptions	832	500	82	-	1,414
Computer costs	6,687	3,030	1,146	-	10,863
Legal and Professional	161	-	-	-	161
Staff Training	2,238	866	514	-	3,618
Repairs and maintenance	221	221	-	-	442
Other charitable expenditure	3,196	5	2	-	3,203
	86,150	64,388	38,106	30,405	219,049
Grant funding of activities (see note 9)	1,085	-	-	-	1,085
Share of support and governance costs (see note 10)					
Support	21,266	15,696	4,645	-	41,607
Governance	5,857	4,324	1,279	-	11,460
	114,358	84,408	44,030	30,405	273,201
Analysis by fund					
Unrestricted funds	89,296	77,940	26,200	-	193,436
Restricted funds	25,062	6,468	17,830	30,405	79,765
	114,358	84,408	44,030	30,405	273,201

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

8 Expenditure on charitable activities

(Continued)

Previous year:	Support Services 2023 £	Awareness and Education 2023 £	Research 2023 £	Community Weekend 2023 £	Total 2023 £
Direct costs					
Staff costs	46,453	45,172	1,918	8,455	101,998
Rates and water	1,678	1,678	-	-	3,356
Insurance	136	129	-	-	265
Light and heat	128	128	-	-	256
Telephone	200	175	-	-	375
Postage and stationery	567	58	-	-	625
Advertising	-	-	400	1	401
Community Weekend	-	-	-	103,798	103,798
Consultancy fees	14,487	3,338	10,938	-	28,763
Conference costs	-	2,140	-	-	2,140
Travel costs	470	79	-	-	549
Subscriptions	1,109	275	31	-	1,415
Computer costs	9,547	1,711	237	-	11,495
Legal and Professional	332	1,244	3,732	-	5,308
Staff Training	2,798	222	462	-	3,482
Repairs and maintenance	141	141	-	-	282
Other charitable expenditure	6	-	1	-	7
	78,052	56,490	17,719	112,254	264,515
Grant funding of activities (see note 9)	3,009	-	-	-	3,009
Share of support and governance costs (see note 10)					
Support	22,807	15,894	2,492	-	41,193
Governance	6,041	4,210	660	-	10,911
	109,909	76,594	20,871	112,254	319,628
Analysis by fund					
Unrestricted funds	61,148	69,395	3,348	1	133,892
Restricted funds	48,761	7,199	17,523	112,253	185,736
	109,909	76,594	20,871	112,254	319,628

9 Grants payable

	Support Services 2024 £	Support Services 2023 £
Grants to individuals	1,085	3,009
	1,085	3,009

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

10 Support costs

	Support costs	Governance costs	2024 Support costs	Governance costs	2023
	£	£	£	£	£
Staff costs	28,854	-	28,854	26,410	26,410
Depreciation	965	-	965	785	785
Insurance	465	-	465	713	713
Telephone	191	-	191	354	354
Postage and stationery	217	-	217	337	337
IT Costs	1,651	-	1,651	3,646	3,646
Training and recruitment costs	3,089	-	3,089	823	823
Premises expenses	2,160	-	2,160	3,840	3,840
Repairs, maintenance and equipment	203	-	203	70	70
Subscriptions	35	-	35	260	260
Travel and subsistence	1,599	-	1,599	1,207	1,207
Sundry costs	41	-	41	333	333
Bank Charges	139	-	139	242	242
Bank Loan interest paid	198	-	198	1,003	1,003
Consultancy fee	1,800	-	1,800	1,170	1,170
Audit fees	-	11,400	11,400	-	10,800
Legal and professional	-	60	60	-	111
	<u>41,607</u>	<u>11,460</u>	<u>53,067</u>	<u>42,022</u>	<u>45,348</u>
Analysed between					
Charitable activities	<u>41,607</u>	<u>11,460</u>	<u>53,067</u>	<u>41,193</u>	<u>52,104</u>

11 Net movement in funds

	2024	2023
	£	£
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	11,400	10,800
Depreciation of owned tangible fixed assets	9,642	9,846
Loss on disposal of tangible fixed assets	266	-
	<u>21,308</u>	<u>20,652</u>

12 Employees

The average monthly number of employees during the year was:

2024	2023
Number	Number
<u>27</u>	<u>26</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 JUNE 2024

12 Employees (Continued)

Employment costs	2024 £	2023 £
Wages and salaries	591,038	520,869
Social security costs	43,464	38,158
Other pension costs	12,961	10,995
	<u>647,463</u>	<u>570,022</u>

Key Management Personnel

The trustees consider four (2023: four) staff members to be Key Management Personnel, the total benefit paid to them is £142,837 (2022: £134,904).

There were no employees whose annual remuneration was more than £60,000.

13 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

14 Tangible fixed assets

	Plant and machinery £	Fixtures & fittings £	Motor vehicles £	Total £
Cost				
At 1 July 2023	32,414	13,200	36,964	82,578
Additions	-	7,808	-	7,808
Disposals	(1,460)	-	-	(1,460)
At 30 June 2024	<u>30,954</u>	<u>21,008</u>	<u>36,964</u>	<u>88,926</u>
Depreciation and impairment				
At 1 July 2023	28,052	7,920	11,787	47,759
Depreciation charged in the year	1,972	2,634	5,036	9,642
Eliminated in respect of disposals	(1,194)	-	-	(1,194)
At 30 June 2024	<u>28,830</u>	<u>10,554</u>	<u>16,823</u>	<u>56,207</u>
Carrying amount				
At 30 June 2024	<u>2,124</u>	<u>10,454</u>	<u>20,141</u>	<u>32,719</u>
At 30 June 2023	<u>4,361</u>	<u>5,280</u>	<u>25,177</u>	<u>34,818</u>

15 Stocks

	2024 £	2023 £
Consumables and branded goods	<u>5,038</u>	<u>3,217</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 JUNE 2024

16 Debtors

	2024	2023
	£	£
Amounts falling due within one year:		
Trade debtors	4,875	2,739
Other debtors	38,607	20,209
Prepayments and accrued income	55,090	23,016
	<u>98,572</u>	<u>45,964</u>

17 Creditors: amounts falling due within one year

	Notes	2024	2023
		£	£
Bank loans	19	10,140	9,891
Trade creditors		88,636	10,733
Other creditors		14,058	12,429
Accruals and deferred income		15,809	20,998
		<u>128,643</u>	<u>54,051</u>

18 Creditors: amounts falling due after more than one year

	Notes	2024	2023
		£	£
Bank loans	19	<u>14,806</u>	<u>24,944</u>

19 Loans and overdrafts

	2024	2023
	£	£
Bank loans	<u>24,946</u>	<u>34,835</u>
Payable within one year	10,140	9,891
Payable after one year	<u>14,806</u>	<u>24,944</u>

20 Retirement benefit schemes

	2024	2023
	£	£
Defined contribution schemes		
Charge to profit or loss in respect of defined contribution schemes	<u>12,961</u>	<u>10,995</u>

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

21 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 July 2023	Incoming resources	ResourcesAt 30 June 2024 expended	
	£	£	£	£
	-	-	-	-
Research	8,018	17,082	(17,817)	7,283
Education & Awareness	3,361	7,477	(6,467)	4,371
Community Weekend	-	30,405	(30,405)	-
Support Services	14,600	47,591	(24,958)	37,233
New Born Screening	32,078	-	(13)	32,065
Children's Support Tools	94	280	(105)	269
Alexander's Disease	1,200	-	-	1,200
	<u>59,351</u>	<u>102,835</u>	<u>(79,765)</u>	<u>82,421</u>
Previous year:	At 1 July 2022	Incoming resources	ResourcesAt 30 June 2023 expended	
	£	£	£	£
	-	20,594	(12,576)	8,018
Research	-	20,594	(12,576)	8,018
Education & Awareness	2,511	8,049	(7,199)	3,361
Family Weekend	-	112,253	(112,253)	-
Support Services	21,049	28,678	(35,127)	14,600
New Born Screening	37,026	-	(4,948)	32,078
Children's Support Tools	13,487	240	(13,633)	94
Alexander's Disease	1,200	-	-	1,200
	<u>75,273</u>	<u>169,814</u>	<u>185,736</u>	<u>59,351</u>

Research fund – A pool of funds to enable Alex TLC to contribute to and promote relevant and approved research activities.

Education & Awareness – A fund for work undertaken to: 1. raise awareness of leukodystrophy both publicly and within the medical community 2. educate patients, their families and involved professionals to ensure best practice and equity in care for those affected by leukodystrophy.

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

21 Restricted funds

(Continued)

Community Weekend fund – organisation of a patient, carer and professional conference incorporating formal and informal activities for all age groups, relevant speakers and workshops along with venue and hosting costs

Support Services – A fund for work undertaken in the provision of support activities.

New Born Screening Fund - A fund to cover the costs of Alex TLC's newborn screening campaign for adrenoleukodystrophy.

Children's Support Tools fund - A fund for development of resources to assist children and young people to understand their or a loved one's diagnosis and prognosis.

Alexander's Disease - a fund restricted to development of support tools specifically for those affected by Alexander's Disease.

22 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 July 2023	Incoming resources	ResourcesAt 30 June 2024 expended	
	£	£	£	£
General funds	234,105	862,383	(892,392)	204,096
	=====	=====	=====	=====
Previous year:	At 1 July 2022	Incoming resources	ResourcesAt 30 June 2023 expended	
	£	£	£	£
General funds	250,769	779,412	(796,076)	234,105
	=====	=====	=====	=====

23 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
	2024	2024	2024
	£	£	£
At 30 June 2024:			
Tangible assets	32,719	-	32,719
Current assets/(liabilities)	186,183	82,421	268,604
Long term liabilities	(14,806)	-	(14,806)
	=====	=====	=====
	204,096	82,421	286,517
	=====	=====	=====

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

23 Analysis of net assets between funds

(Continued)

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
At 30 June 2023:			
Tangible assets	34,818	-	34,818
Current assets/(liabilities)	224,231	59,351	283,582
Long term liabilities	(24,944)	-	(24,944)
	<u>234,105</u>	<u>59,351</u>	<u>293,456</u>

24 Operating lease commitments

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2024 £	2023 £
Within one year	89,380	96,130
Between two and five years	183,254	163,884
	<u>272,634</u>	<u>260,014</u>

25 Related party transactions

There were no disclosable related party transactions during the year (2023 - Nil). There is no ultimate controlling party.

26 Cash generated from operations

	2024 £	2023 £
Deficit for the year	(6,939)	(32,586)
Adjustments for:		
Investment income recognised in statement of financial activities	(3,632)	(1,537)
Loss on disposal of tangible fixed assets	266	-
Depreciation and impairment of tangible fixed assets	9,642	9,846
Movements in working capital:		
(Increase)/decrease in stocks	(1,821)	660
(Increase)/decrease in debtors	(52,608)	20,047
Increase in creditors	74,343	15,762
Cash generated from operations	<u>19,251</u>	<u>12,192</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2024

27 Analysis of changes in net funds

	At 1 July 2023 £	Cash flows £	At 30 June 2024 £
Cash at bank and in hand	288,452	5,185	293,637
Loans falling due within one year	(9,891)	(249)	(10,140)
Loans falling due after more than one year	(24,944)	10,138	(14,806)
	<u>253,617</u>	<u>15,074</u>	<u>268,691</u>