

Charity registration number 1106008 (England and Wales)

Charity registration number SC051539 (Scotland)

Company registration number 05142341

ALEX, THE LEUKODYSTROPHY CHARITY
ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2025

ALEX, THE LEUKODYSTROPHY CHARITY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	L Milne	
	O Bostock	
	I Idafar	
	E Hadfield-Hudson	
	T Sandys-Winsch	
	G Sarig	
	T Dalton	
	N Shiroi	
	S Baldini	(Appointed 6 September 2024)
	R Singh	(Appointed 1 September 2025)
Secretary	Sara Hunt	
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 2025

The trustees present their annual report and financial statements for the year ended 30 June 2025.

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.

The trustees confirm that they have had due regard to the Charity Commission's guidance on public benefit when planning and delivering the charity's activities. Our services are provided to support anyone affected by leukodystrophy, and we continue to improve equitable access by increasing awareness, expanding outreach to under-represented groups, and delivering tailored support that reduces isolation, improves wellbeing, and enhances understanding of the condition. Through peer support, counselling, advocacy, information services and community events, the charity demonstrably benefits beneficiaries and their families, ensuring support is accessible regardless of background, geography or financial circumstances.

Achievements and performance

Organisation

Despite the challenges experienced by the charity sector as a whole, Alex TLC were able to celebrate many positives during this period.

Our efforts to improve awareness of our organisation saw the biggest year-on-year increases experienced since our humble beginnings in 2004. We welcomed 257 new beneficiaries affected by leukodystrophy, a 64% increase on the previous year, delivering 2,556 support activities, up 33% with the total number of beneficiaries on our database growing to 2,229 across 58 countries. This clearly demonstrates the impact of the launch of our new website in April 2024, improvements made to online visibility and the presence of support staff at NHS clinics. We were particularly pleased to see these changes effecting an unparalleled increase in new beneficiaries from under-represented communities seeking support, with numbers rising from 8 to 45 compared with last year.

Our communications continued to be well-received by our community, with open rates exceeding 41% across all regular mailings. Our new website helped to boost newsletter subscriptions by 25% on the previous year, with visits increasing by a significant 59%. We were especially pleased to see visits to our condition, support and research pages rise collectively by 80%. Staff worked diligently to understand the complexities of social media resulting in overall engagement growth of 35% (Facebook 73%). We also decided to discontinue use of X, taking the view that our values no longer aligned with the platform.

Peer networking opportunities remain a mainstay of the support we offer. We connected 88 beneficiaries, helping to reduce their feelings of isolation, a 13% year-on-year increase, with membership of our closed Facebook support group rising by 28% to 173. We also supported beneficiaries suffering from extremely rare leukodystrophies to set up WhatsApp groups monitored by support staff.

Our new Grants and Trusts Fundraiser has not only increased our capacity to secure funding but has also been instrumental in a review of our impact reporting framework. This has resulted in improved and streamlined surveys encouraging more beneficiaries to participate. As part of this work, we are establishing a diverse portfolio of case studies covering the various aspects of living with these cruel and devastating conditions and have introduced new methods to gauge both the short- and long-term impact of our activities.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 30 JUNE 2025

We published three Impact Reports across the period:

Charity Impact Report - *“Alex TLC has been a huge support for the whole family.”, “...a lifeline to me.”*

- 75% said Alex TLC was the most beneficial support service
- 79% agreed Alex TLC helped them feel less isolated
- 75% agreed Alex TLC helped them cope with their/their loved one's condition
- 99% agreed with our decision to become more involved in research
- 78% agreed Alex TLC had a positive impact on their lives

Support Services Impact Report – *“...answered my questions with genuine compassion ...helpful and comforting.”*

- 95% found one to one support helpful, 5% somewhat helpful
- 100% found our peer support programme helpful and would use again
- 71% found our professional counselling service helpful, 29% somewhat helpful
- 100% said our counselling service helped them feel better able to cope with their leukodystrophy situation.

Community Weekend Impact Report – *“A great weekend, being in a room full of people on the same journey who get it. I did not feel judged and felt part of something for the first time in years”*

- 100% would attend again
- 97% said the event helped them connect with others
- 94% said it increased understanding of the leukodystrophy affecting them
- 100% of beneficiaries and professionals said the event was useful

Raising awareness of both leukodystrophy and Alex TLC is a high priority for the organisation, and we engage in various awareness-raising activities. Our new website and improved social media skills continue to improve this area, ensuring more people can find us and understand the work we do. A significant part of awareness raising are our two major campaigns, Leukodystrophy Awareness Month in September and Rare Disease Day in February, with both increasing engagement statistics during the months they run. This year Leukodystrophy Awareness month doubled engagement statistics across all our social media channels (Facebook, Instagram and LinkedIn).

Our stakeholder relationships are highly valued, and we were able to attract new relationships during the period as well as progress new projects:

- We became the charity partner for a large sports corporate raising both awareness and significant income
- We established mutual links with two condition-specific leukodystrophy charities, and now share resources and communications regularly
- Worked with leukodystrophy specialists to develop and share literature to encourage adult males with adrenoleukodystrophy to have potentially life-saving annual MRI scans
- Worked with pharmaceutical companies to co-produce patient facing clinical trial literature and communications
- Worked with the NHS Inherited White Matter Disorder (IWMD) Service to launch the patient registry and develop patient literature, as well as presenting at their professional study days
- Established a working group to improve diagnosis of adrenoleukodystrophy in patients with primary adrenal insufficiency
- Published translations of our children's support book in German and Spanish

The retail business suffered a significant decline in expected contribution, due to salary and cost of living increases. The overall contribution from our five charity shops was £53,849 (2024: £81,218), a 34% decrease. Unrestricted grants and donations continued to grow to £132,135 (2024: £112,444), an increase of 15%.

Internally we promoted the Support Services Manager to Director of Support in recognition of the additional leadership duties undertaken. We also delegated greater leadership responsibility to the Senior Management Team, enabling the Chief Executive Officer to focus on the wider strategic challenges of the year. As such, there has been a focus on succession planning, risk management and optimisation of income streams, including additional hours for fundraising staff and a review of our charity shop business.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

Environmental Sustainability

Alex TLC is committed to reducing its environmental impact and operates in line with a comprehensive Environmental Policy Statement. Sustainability principles are embedded throughout our activities, we actively promote reusing and recycling of goods through our five charity shops. We prioritise environmentally responsible sourcing, with office furniture and equipment regularly obtained from our charity shop donations or external recycling schemes and the purchase of repurposed IT equipment where possible. We continue to digitalise processes, especially for the retail team, through development of a new staff Intranet. In line with this approach, our Community Weekend information, literature and feedback surveys moved to an online format three years ago which has been welcomed by our community. Recognising that some in our community may face challenges accessing digital information, we always provide hard-copy alternatives or personalised support as needed.

Charitable objectives

Across the year Alex TLC staff:

- welcomed 257 new beneficiaries
- supported 500 beneficiaries across 2,265 support activities including one to one conversations, home visits and advocacy, digital wellbeing sessions and face to face get togethers
- delivered 171 professional counselling sessions and wellbeing calls to 32 beneficiaries
- connected 88 beneficiaries to build supportive, long-lasting relationships
- were invited to present at 8 events including Manchester NHS IWMD Service study day, MSC genomics at Imperial College in London, International Society for Neonatal Screening in Luxembourg
- attended 28 stakeholder conferences and events including Genomics England, ALD Connect, European Leukodystrophy Association, Global Leukodystrophy Initiative, NHS Genomics Healthcare Summit, stand at British Paediatrics Neurology Association
- were involved in 199 stakeholder meetings including NHSE IWMD Service and Registry development committee, Genetic Alliance Trustee Board, European Reference Network for Rare Neurological Disorders, Generation Study, Rare Disease Advisory Group, Childhood Dementia Organisation
- encouraged 92,361 engagements on our social media channels
- attracted 61,539 website visitors
- were mentioned in the press 5 times including BBC news and Rare Revolutions Magazine

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

NHSE IWMD Service and Patient Registry – This vital patient service and registry continues to thrive, and as lead patient partner we play an important role in ensuring patient voice remains front and centre of service priorities. The patient registry launched in spring 2025 and will become a vital resource for researchers and decision makers in years to come. Our staff were able to start visiting centre clinics, supporting 26 patients at 10 clinics. Across the year Alex TLC referred 22 patients to the service, and service centre staff referred 34 patients to Alex TLC, demonstrating the mutual benefits of the relationship.

Newborn Screening – Disappointingly, the expected review for adrenoleukodystrophy has been delayed due to reduced capacity at the National Screening Committee (NSC). However, we were able to secure a guarantee that an additional evidence submission would be reviewed during our next reporting period. A rapid review of metachromatic leukodystrophy was announced in May 2025 and we developed a comprehensive response template for our MLD community.

Community Weekend – We continued to honour our commitment to an annual event with our 2024 event held again in Birmingham, attracting 192 attendees (a 37% year-on-year increase). We launched a rolling fundraising strategy with our corporate partners to ensure long term stability for this project; funding proposals now encompass a three-year cycle bringing the event to the north, midlands and south of the country to improve access for our community.

Challenges

As with many in the charity sector, we have faced significant challenges in income generation during the period against a backdrop of rising costs, beneficiary numbers and requests for support.

While the rise in the number of beneficiaries coming to us for support is encouraging, there is a real risk that current support staffing levels will not be able to meet future need. Additional resources are urgently needed to maintain the quality of support we can offer alongside meeting rising demand. Our 2025-26 grant fundraising strategy is focussed on securing the necessary funds for an additional support staff member.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

Our biggest financial burden has been successive increases to minimum wage levels alongside increases to Employers' National Insurance contributions. Collectively these have added £90,000 to our annual salary costs from April 2025. Coupled with rising costs, the collapse of the rag market (rag prices dropped from 50p a kilo to less than 10p a kilo during the period) and the absence of key staff, this has severely impacted the contribution from our charity retail business. A retail consultant has been sourced to identify areas of improvement of our retail business for the 2025-26 period alongside new staff members and a thorough financial review. Modest investment in this area will give us the understanding required to optimise this income stream.

Two of our pharmaceutical industry supporters withdrew their leukodystrophy research programmes citing poor trial results and financial issues. We are monitoring this area closely to identify future risks to this funding stream, for example geopolitical events. Our research analyst continuously seeks out new industry partners within a robust horizon scanning and stakeholder relationship framework ensuring that we are quick to react to new opportunities as they arise. We have an excellent relationship with our existing stakeholders which gives scope to explore further industry support for 2025-26.

Staff absence due to illness contributed to a reduction in presenting opportunities for the period, and we are training additional staff members to increase our resource for these activities.

Future Impact

Our ability to grow, despite the challenges identified, is our utmost priority for the coming year.

The review of our retail business will be essential to ensure we can optimise this income stream, and we have sourced an experienced consultant to implement some small measures to improve procedures. The introduction of the consultant, new staff and management apprentices to focus on visual merchandising, online sales and shop processes should improve footfall and income. Nevertheless, we are closely monitoring this area and reviewing the options available to us.

Working with our industry partners, we have identified the potential of using our annual Science Day and Community Weekend to offer more value for a wider range of medical professionals, the pharmaceutical industry and disability and medical equipment suppliers, creating additional income. There is generally low awareness of Leukodystrophy conditions within the non-leukodystrophy specialist community. Therefore, this affords opportunities for increased medical knowledge of these conditions which will translate into better treatment and care for leukodystrophy patients. Our autumn 2026 event will be critical to testing this opportunity and we will use the 2025-26 period to develop the strategy for this. We have a variety of new projects in our pipeline but are mindful not to overstretch staff. Workloads will be monitored closely to ensure we have secured sufficient resources to undertake new work and opportunities as they arise.

Fundraising practices

The trustees confirm that the charity conducts all fundraising activities in line with the Code of Fundraising Practice and has had due regard to the guidance of the Fundraising Regulator. The charity does not use professional fundraisers.

Financial review

Income Summary

For clarity, in this narrative section, we present our retail operations on a net contribution basis rather than showing the full shop turnover as income. This approach provides a more meaningful picture of the charity's financial performance, as the shops generate substantial gross income but also significant associated costs. It is also the method we use for internal management reporting, as it gives trustees a clearer view of the net funds generated to support our charitable work. Trustees also receive regular reports showing the full gross income and expenditure for our retail operations, ensuring complete transparency and understanding of the underlying figures. This presentation is for explanation only; the statutory financial statements continue to comply fully with the Charity SORP (FRS 102) and include the full gross income and expenditure from trading activities.

For the year ending 30 June 2025, the net contribution from our retail operations was £52,571 (2024: £83,073), based on shop income of £703,730 (2024: £718,818) and expenditure of £651,159 (2024: 635,745). Total charitable income excluding trading turnover was £356,167 (2024: 238,408), resulting in a combined total income of £408,738 (2024: £321,481) for reporting purposes.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 30 JUNE 2025*

Our main income sources this year were:

- Donations from individuals – £132,483 (32%) (2024: 34%)
- Charitable organisations – £93,929 (23%) (2024: 25%)
- Pharma organisations – £105,280 (26%) (2024: 8%)
- Other corporate donors – £24,475 (6%) (2024: 0%)
- Net contribution from trading activities – £52,571 (13%) (2024: 26%)

Presenting the shops on a contribution basis allows the Board, supporters, and stakeholders to more clearly understand the impact of both donated income and the net funds generated by our retail activity. It ensures transparency while highlighting the positive role our shops play in supporting our charitable work.

The reduction in retail contribution reflects the challenging economic climate and increased operating costs. Our teams are focused on improving performance through tighter cost control and operational efficiencies, and we remain committed to strengthening the contribution of our retail operations in the year ahead.

We are also encouraged by the growth in donations and grant income during the year, particularly as the wider sector continues to face increasing competition for external funding. Strong support from individuals, charitable organisations, pharma partners and corporate donors has helped to strengthen our overall financial position and maintain the delivery of our charitable work.

The comparative figures for 2024 have been adjusted to reclassify other income as charitable activities for better transparency and consistency.

Expenditure Summary

Total expenditure (excluding retail) for the year was £374,428 (2024: £328,735). Of this 71% (2024: 67%) was spent on charitable activities, 19% (2024: 17%) on fundraising and 10% (2024: 16%) on support costs. The overall increase in expenditure was primarily due to the change in the timing of the Community Weekend from May 2024 to October 2024, resulting in no event taking place within the 2023/24 financial year. Fundraising costs rose following the recruitment of a Grants and Trusts Fundraiser, whose work has already resulted in additional income.

Financial Position Overview

At 30 June 2025, total assets stood at £374,049 (2024: £397,247), including cash reserves of £217,770 (2024: £288,452). Liabilities were £67,801 (2024: £143,449) with the reduction compared with the previous year reflecting creditors outstanding at the 2024 year-end relating to the postponed Community Weekend. This resulted in net assets of £337,879 (2024: £286,517).

Cash Flow Summary

The charity maintained a positive cash flow throughout the year. At 30 June 2025, there was a net cash outflow of £75,867, largely due to timing differences of £93,000 relating to the restricted Community Weekend costs which will unwind in September 2025. Despite this, liquidity and overall financial stability remain strong.

Key Points on Budget Performance

Budgeted income for the year was £446,930, with actual income £21,085 below this target. This shortfall was mainly due to lower-than-expected retail contributions (£77,959 under budget), partly offset by stronger-than-budgeted grant and donation income.

Expenditure was £56,896 below budget, including £25,000 of timing differences in the Community Weekend costs and further cost savings achieved across several areas. As a result, the unrestricted deficit for the year was £2,110 against a budgeted surplus of £630. Given the unexpected rise in salary costs and challenging market conditions, this outcome is considered reasonable and within an acceptable variance.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 30 JUNE 2025*

Reserve Policy

At the balance sheet date, unrestricted funds totalled £201,986 (2024: £204,096), and restricted funds £135,893 (2024: £82,421).

The charity's policy is to maintain unrestricted reserves at a level sufficient to cover approximately three months of operating costs (around £260,000).

Although unrestricted reserves were marginally below budget at year end, this represents a positive outcome in the context of rising costs and wider financial pressures across the sector. Trustees remain focused on sustaining financial resilience and actively pursuing opportunities to strengthen and diversify income.

Future Outlook

For the year ahead, budgeted income is £401,981 with an anticipated deficit of £40,741, largely reflecting increased salary costs. The charity will use this year to review processes and explore additional income opportunities to strengthen future financial sustainability.

We anticipate further growth through new grant applications and Community Weekend funding, while taking a cautious approach to retail income forecasts. Our focus remains on expanding charitable activities, strengthening sustainability, and maximising our impact within the community.

Plans for future periods

Work areas for 2025/26 include:

- Further translations of our children's support book "When My Brother Got Ill – A story of Adrenoleukodystrophy"
- Five-year strategy for development of further children's and young peoples' support resources
- Schedule of emotional wellbeing activities for community
- Implementation of reviewed monitoring and evaluation processes including short- and long-term impact reporting
- Co-development of a communication and awareness strategy with the NHS IWMD Service and Registry
- Annual Community Weekend
- Restructure of our Science Day to encourage additional professional and industry attendees
- Creation of video resources for online promotion
- Implementation of new campaign "Life with leukodystrophy"
- Apply for PIF tick accreditation
- Awareness campaign within charity retail business
- Develop and implement a major donor strategy
- Explore the use of AI to enhance work activities

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 2025

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	
O Bostock	
T Watkins	(Resigned 16 September 2024)
G Metcalf	(Resigned 28 May 2025)
J Livingston	(Resigned 5 September 2025)
I Idafar	
E Hadfield-Hudson	
K Amber	(Resigned 28 August 2025)
T Sandys-Winsch	
G Sarig	
T Dalton	
N Shiroi	
S Tan	(Resigned 31 August 2025)
S Baldini	(Appointed 6 September 2024)
R Singh	(Appointed 1 September 2025)

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 accompanied by appointing trustees with complementary skills, e.g. legal, finance, administration or relevant professional experience and knowledge.

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

Equality, Diversity and Inclusion

Equality, diversity and inclusion are central to the culture and governance of Alex TLC. We are committed to ensuring equitable access to support for all those affected by leukodystrophy, guided by our annually reviewed Equality and Diversity Policy. We continue to monitor and address disparities in engagement to ensure beneficiaries from under-represented communities can access timely and appropriate support.

Ensuring that our organisation reflects the community we serve is essential. We have a diverse workforce which includes staff members and Board Trustees from different backgrounds and communities along with those with lived experience of leukodystrophy. This ensures inclusion is at the core of our governance, strategy and service development.

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. Overall the charity 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.

Safeguarding

The trustees confirm that safeguarding policies and training are in place to protect our vulnerable beneficiaries, and that safeguarding practices are regularly reviewed and monitored.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

Auditor

In accordance with the company's articles, a resolution proposing that Richard Place Dobson Services Limited be reappointed as auditor of the company will be put at a General Meeting.

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

The trustees report was approved by the Board of Trustees.



.....
L Milne
Trustee

Date: 28 January 2026



Iraj Idafar (Feb 16, 2026 09:45:18 GMT)

I Idafar
Trustee

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF TRUSTEES RESPONSIBILITIES

FOR THE YEAR ENDED 30 JUNE 2025

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; 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. 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 2025 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 2025 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.

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 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 and donations received and the level of shop income. 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

18 February 2026

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 2025

Current financial year		Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Total 2024 £
	Notes				
Income from:					
Donations and legacies	3	129,760	226,407	356,167	215,000
Charitable activities	4	6,739	-	6,739	4,737
Other trading activities	5	711,107	-	711,107	741,849
Investments	6	3,591	-	3,591	3,632
Total income		<u>851,197</u>	<u>226,407</u>	<u>1,077,604</u>	<u>965,218</u>
Expenditure on:					
Raising funds	7	723,996	-	723,996	698,956
Charitable activities	8	129,311	172,935	302,246	273,201
Total expenditure		<u>853,307</u>	<u>172,935</u>	<u>1,026,242</u>	<u>972,157</u>
Net income/(expenditure) and movement in funds		(2,110)	53,472	51,362	(6,939)
Reconciliation of funds:					
Fund balances at 1 July 2024		<u>204,096</u>	<u>82,421</u>	<u>286,517</u>	<u>293,456</u>
Fund balances at 30 June 2025		<u>201,986</u>	<u>135,893</u>	<u>337,879</u>	<u>286,517</u>

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

STATEMENT OF FINANCIAL ACTIVITIES (CONTINUED) INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 JUNE 2025

Prior financial year		Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
	Notes			
Income from:				
Donations and legacies	3	112,445	102,555	215,000
Charitable activities	4	4,457	280	4,737
Other trading activities	5	741,849	-	741,849
Investments	6	3,632	-	3,632
Total income		862,383	102,835	965,218
Expenditure on:				
Raising funds	7	698,956	-	698,956
Charitable activities	8	193,436	79,765	273,201
Total expenditure		892,392	79,765	972,157
Net income/(expenditure) and movement in funds		(30,009)	23,070	(6,939)
Reconciliation of funds:				
Fund balances at 1 July 2023		234,105	59,351	293,456
Fund balances at 30 June 2024		204,096	82,421	286,517

ALEX, THE LEUKODYSTROPHY CHARITY

BALANCE SHEET

AS AT 30 JUNE 2025

	Notes	2025 £	£	2024 £	£
Fixed assets					
Tangible assets	14		31,631		32,719
Current assets					
Stocks	15	2,872		5,038	
Debtors	16	152,907		98,572	
Cash at bank and in hand		218,270		293,637	
		<u>374,049</u>		<u>397,247</u>	
Creditors: amounts falling due within one year	17	<u>(63,390)</u>		<u>(128,643)</u>	
Net current assets			310,659		268,604
Total assets less current liabilities			342,290		301,323
Creditors: amounts falling due after more than one year	18		<u>(4,411)</u>		<u>(14,806)</u>
Net assets			<u>337,879</u>		<u>286,517</u>
The funds of the charity					
Restricted income funds	21	135,893		82,421	
Unrestricted funds	22	201,986		204,096	
		<u>337,879</u>		<u>286,517</u>	

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 2025.

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.


ALEX, THE LEUKODYSTROPHY CHARITY

BALANCE SHEET (CONTINUED)

AS AT 30 JUNE 2025

The financial statements have been audited in accordance with section 144 of the Charities Act 2011, section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and section 106 of the Charities Accounts (Scotland) Regulations 2006 for the year ended 30 June 2025.

The financial statements were approved by the trustees on 28 January 2026



.....
L Milne
Trustee



Iraj.Idafar (Feb 16, 2026 09:45:18 GMT)

I Idafar
Trustee

Company registration number 05142341 (England and Wales)

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 30 JUNE 2025

	Notes	2025 £	£	2024 £	£
Cash flows from operating activities					
Cash (absorbed by)/generated from operations	26		(60,407)		19,250
Investing activities					
Purchase of tangible fixed assets		(8,412)		(7,808)	
Investment income received		3,591		3,632	
		<u> </u>		<u> </u>	
Net cash used in investing activities			(4,821)		(4,176)
Financing activities					
Repayment of bank loans		(10,139)		(9,889)	
		<u> </u>		<u> </u>	
Net cash used in financing activities			(10,139)		(9,889)
Net (decrease)/increase in cash and cash equivalents			(75,367)		5,185
Cash and cash equivalents at beginning of year			293,637		288,452
			<u> </u>		<u> </u>
Cash and cash equivalents at end of year			218,270		293,637
			<u> </u>		<u> </u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2025

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 Basis of preparation

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 2025

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.

The charity has a capitalisation policy in place to capitalise fixed assets costing more than £500. All computers and laptops are capitalised, irrespective of their individual cost.

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 2025

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 2025

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 Income from donations and legacies

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Donations and gifts	116,058	46,300	162,358	106,845	3,655	110,500
Grants	13,702	180,107	193,809	5,600	98,900	104,500
	<u>129,760</u>	<u>226,407</u>	<u>356,167</u>	<u>112,445</u>	<u>102,555</u>	<u>215,000</u>
Grants						
The National Lottery						
Community Funds	-	34,487	34,487	-	34,150	34,150
Ionis Pharmaceuticals	-	17,000	17,000	-	10,000	10,000
Garfield Weston Foundation	-	20,000	20,000	-	20,000	20,000
Spur Therapeutics	-	-	-	-	5,000	5,000
Vigil Neuroscience	-	12,700	12,700	-	10,000	10,000
End Alexander Disease	-	1,000	1,000	-	-	-
The British Trust for the Myelin Project	-	8,392	8,392	-	-	-
BBC Children in Need	-	15,000	15,000	-	-	-
Forge Biologics	-	1,988	1,988	-	-	-
BridgeBio	-	18,232	18,232	-	-	-
Minoryx Therapeutics	13,702	23,198	36,900	-	-	-
Orchard Therapeutics	-	10,550	10,550	-	-	-
Leukolabs	-	1,000	1,000	-	-	-
SynaptixBio	-	1,510	1,510	-	-	-
Other	-	15,050	15,050	5,600	19,750	25,350
	<u>13,702</u>	<u>180,107</u>	<u>193,809</u>	<u>5,600</u>	<u>98,900</u>	<u>104,500</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

4 Income from charitable activities

	Support Services	Awareness and Education	Total	Support Services	Awareness and Education	Total
	2025	2025	2025	2024	2024	2024
	£	£	£	£	£	£
Other income	3,122	3,617	6,739	700	4,037	4,737
	<u>3,122</u>	<u>3,617</u>	<u>6,739</u>	<u>700</u>	<u>4,037</u>	<u>4,737</u>
Analysis by fund						
Unrestricted funds	3,122	3,617	13,478	700	3,757	4,457
Restricted funds	-	-	-	-	280	280
	<u>3,122</u>	<u>3,617</u>	<u>13,478</u>	<u>700</u>	<u>4,037</u>	<u>4,737</u>

5 Income from other trading activities

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Fundraising events	7,815	24,886
Shop income	703,292	716,963
	<u>711,107</u>	<u>741,849</u>

6 Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Interest receivable	3,591	3,632
	<u>3,591</u>	<u>3,632</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

7 Expenditure on raising funds

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Fundraising and publicity		
Other fundraising costs	15,593	12,618
Staff costs	56,587	42,916
	<hr/>	<hr/>
	72,180	55,534
	<hr/>	<hr/>
Trading costs		
Operating charity shops	215,094	206,794
Other trading activities	657	7,677
Staff costs	427,563	420,008
Depreciation and impairment	8,502	8,943
	<hr/>	<hr/>
	651,816	643,422
	<hr/>	<hr/>
Total costs	723,996	698,956
	<hr/>	<hr/>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

8 Expenditure on charitable activities

	Support Services	Awareness and Education	Research	Community Weekend	Total
	2025	2025	2025	2025	2025
	£	£	£	£	£
Direct costs					
Staff costs	76,469	43,708	34,687	21,220	176,084
Rates and water	1,566	1,505	-	-	3,071
Insurance	233	233	1,494	-	1,960
Light and heat	153	153	39	-	345
Telephone	202	142	5	-	349
Postage and stationery	662	69	-	-	731
Advertising	-	697	35	-	732
Community Weekend	302	-	-	55,438	55,740
Consultancy fees	-	570	480	-	1,050
Conference costs	-	1,788	-	-	1,788
Travel costs	1,056	-	-	1,907	2,963
Subscriptions	754	741	34	-	1,529
Computer costs	4,377	3,349	1,532	92	9,350
Legal and Professional	124	-	-	-	124
Staff Training	3,463	378	41	36	3,918
Repairs and maintenance	232	232	-	-	464
Other charitable expenditure	2,899	104	-	559	3,562
	92,492	53,669	38,347	79,252	263,760
Grant funding of activities (see note 9)	2,244	-	-	100	2,344
Share of support and governance costs (see note 10)					
Support	12,932	7,326	2,617	-	22,875
Governance	7,500	4,249	1,518	-	13,267
	115,168	65,244	42,482	79,352	302,246
Analysis by fund					
Unrestricted funds	51,985	58,072	19,254	-	129,311
Restricted funds	63,183	7,172	23,228	79,352	172,935
	115,168	65,244	42,482	79,352	302,246

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

8 Expenditure on charitable activities

(Continued)

Previous year:	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

9 Grants payable

	Support Services	Community Weekend	Total	Support Services
	2025	2025	2025	2024
	£	£	£	£
Grants to individuals	2,244	100	2,344	1,085

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

10 Support costs allocated to activities

	2025 £	2024 £
Staff costs	15,807	28,854
Depreciation	998	965
Insurance	466	465
Telephone	190	191
Postage and stationery	60	217
IT costs	1,742	1,651
Training and recruitment costs	126	3,089
Premises expenses	2,294	2,160
Repairs, maintenance and equipment	197	203
Subscriptions	101	35
Travel and subsistence	645	1,599
Sundry costs	-	41
Bank charges	117	139
Bank loan interest paid	132	198
Consultancy fee	-	1,800
Governance costs	13,267	11,460
	<u>36,142</u>	<u>53,067</u>
Analysed between:		
Support Services	20,432	27,123
Awareness and Education	11,575	20,020
Research	4,135	5,924
	<u>36,142</u>	<u>53,067</u>

11 Net movement in funds

	2025 £	2024 £
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	11,940	11,400
Depreciation of owned tangible fixed assets	9,472	9,642
Loss on disposal of tangible fixed assets	28	266
	<u></u>	<u></u>

12 Employees

The average monthly number of employees during the year was:

2025 Number	2024 Number
27	27
<u></u>	<u></u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 JUNE 2025

12 Employees (Continued)

Employment costs	2025 £	2024 £
Wages and salaries	616,923	591,038
Social security costs	45,817	43,464
Other pension costs	13,301	12,961
	<u>676,041</u>	<u>647,463</u>

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

Remuneration of key management personnel

The remuneration of key management personnel was as follows:

	2025 £	2024 £
Aggregate compensation	<u>232,619</u>	<u>142,837</u>

The Trustees consider six staff members (2024: four) to be Key Management Personnel, consisting of the Senior Management Team and the Accounts Manager.

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 2024	30,954	21,008	36,964	88,926
Additions	4,502	3,910	-	8,412
Disposals	(2,596)	-	-	(2,596)
	<u>32,860</u>	<u>24,918</u>	<u>36,964</u>	<u>94,742</u>
At 30 June 2025	32,860	24,918	36,964	94,742
Depreciation and impairment				
At 1 July 2024	28,830	10,554	16,823	56,207
Depreciation charged in the year	2,014	3,430	4,028	9,472
Eliminated in respect of disposals	(2,568)	-	-	(2,568)
	<u>28,276</u>	<u>13,984</u>	<u>20,851</u>	<u>63,111</u>
At 30 June 2025	28,276	13,984	20,851	63,111
Carrying amount				
At 30 June 2025	<u>4,584</u>	<u>10,934</u>	<u>16,113</u>	<u>31,631</u>
At 30 June 2024	<u>2,124</u>	<u>10,454</u>	<u>20,141</u>	<u>32,719</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 JUNE 2025

15 Stocks

	2025 £	2024 £
Consumables and branded goods	2,872	5,038

16 Debtors

	2025 £	2024 £
Amounts falling due within one year:		
Trade debtors	22,827	4,875
Other debtors	30,344	38,607
Prepayments and accrued income	99,736	55,090
	152,907	98,572

17 Creditors: amounts falling due within one year

	Notes	2025 £	2024 £
Bank loans	19	10,396	10,140
Other taxation and social security		13,972	10,065
Trade creditors		19,597	88,636
Other creditors		5,525	3,993
Accruals and deferred income		13,900	15,809
		63,390	128,643

18 Creditors: amounts falling due after more than one year

	Notes	2025 £	2024 £
Bank loans	19	4,411	14,806

19 Loans and overdrafts

	2025 £	2024 £
Bank loans	14,807	24,946
Payable within one year	10,396	10,140
Payable after one year	4,411	14,806

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

20 Retirement benefit schemes

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.

At the year end, the charity owed £3,403.74 to the pension provider (2024: £3,101.92).

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 2024	Incoming resources	Resources expended	At 30 June 2025
	£	£	£	£
Research	7,283	22,013	(23,227)	6,069
Education & Awareness	4,371	5,956	(6,902)	3,425
Community Weekend	-	150,337	(79,352)	70,985
Support Services	37,233	48,101	(63,156)	22,178
New Born Screening	32,065	-	(29)	32,036
Children's Support Tools	269	-	(269)	-
Alexander's Disease	1,200	-	-	1,200
	<u>82,421</u>	<u>226,407</u>	<u>(172,935)</u>	<u>135,893</u>
Previous year:	At 1 July 2023	Incoming resources	Resources expended	At 30 June 2024
	£	£	£	£
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>

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 2025

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 2024	Incoming resources	ResourcesAt 30 June 2025 expended	
	£	£	£	£
General funds	204,096	851,197	(853,307)	201,986
	=====	=====	=====	=====
Previous year:	At 1 July 2023	Incoming resources	ResourcesAt 30 June 2024 expended	
	£	£	£	£
General funds	234,105	862,383	(892,392)	204,096
	=====	=====	=====	=====

23 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
	2025	2025	2025
	£	£	£
At 30 June 2025:			
Tangible assets	31,631	-	31,631
Current assets/(liabilities)	174,766	135,893	310,659
Long term liabilities	(4,411)	-	(4,411)
	=====	=====	=====
	201,986	135,893	337,879
	=====	=====	=====

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

23 Analysis of net assets between funds

(Continued)

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 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)
	<u>204,096</u>	<u>82,421</u>	<u>286,517</u>

24 Operating lease commitments

Lessee

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:

	2025 £	2024 £
Within one year	118,255	89,380
Between two and five years	108,999	183,254
	<u>227,254</u>	<u>272,634</u>

25 Related party transactions

There were no disclosable related party transactions during the year (2024 - Nil). There is no ultimate controlling party.

26 Cash (absorbed by)/generated from operations

	2025 £	2024 £
Surplus/(deficit) for the year	51,362	(6,939)
Adjustments for:		
Investment income recognised in statement of financial activities	(3,591)	(3,632)
Loss on disposal of tangible fixed assets	28	266
Depreciation and impairment of tangible fixed assets	9,472	9,642
Movements in working capital:		
Decrease/(increase) in stocks	2,166	(1,821)
(Increase) in debtors	(54,335)	(52,609)
(Decrease)/increase in creditors	(65,509)	74,343
Cash (absorbed by)/generated from operations	<u>(60,407)</u>	<u>19,250</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2025

27 Analysis of changes in net funds

	At 1 July 2024 £	Cash flows £	At 30 June 2025 £
Cash at bank and in hand	293,637	(75,367)	218,270
Loans falling due within one year	(10,140)	(256)	(10,396)
Loans falling due after more than one year	(14,806)	10,395	(4,411)
	<u>268,691</u>	<u>(65,228)</u>	<u>203,463</u>