

Alex, The Leukodystrophy Charity

England & Wales · Charity number 1106008

Details

Other names ALD LIFE

Status Registered

Legal form Charitable company

Company number [05142341](#)

Registered 2004-09-23

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

Contact

Address Alex
The Leukodystrophy Charity
45 Peckham High Street
London

Phone 02077014388

Email info@alextlc.org

Website www.alextlc.org

Activities

Objects: 1. The relief of sickness of people with leukodystrophy (also known as Inherited White Matter Disorders) and their parents and carers;2 To promote medical research into leukodystrophy and the publication of useful results of such research for the benefit of the public; and3 To advance the education of the public in leukodystrophy.

Activities: A charity to promote awareness, research & prevention of leukodystrophy.Alex, The Leukodystrophy Charity enables sufferers of leukodystrophy worldwide a forum to come together to support and advise each other. We provide financial & emotional support as well as practical advice & updates on research innovations, promote and fund research & education for medical professionals.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups

Geography

- **Area of benefit:** NOT DEFINED. IN PRACTICE WORLDWIDE
- Afghanistan
- Akrotiri
- Albania
- Algeria
- American Samoa
- Andorra
- Angola
- Anguilla
- Antarctica
- Antigua And Barbuda
- Argentina
- Armenia
- Aruba
- Australia
- Austria
- Azerbaijan
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
- Bosnia And Herzegovina
- Botswana
- Brazil
- British Indian Ocean Territory
- British Virgin Islands
- Brunei
- Bulgaria

- Burkina Faso
- Burma
- Burundi
- Cambodia
- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- Christmas Island
- Cocos (KEELING) ISLANDS
- Colombia
- Comoros
- Congo
- Congo (Democratic Republic)
- Cook Islands
- Costa Rica
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Denmark
- Dhekelia
- Djibouti
- Dominica
- Dominican Republic
- East Timor
- Easter Island
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea

- Eritrea
- Estonia
- Eswatini
- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
- Finland
- France
- French Guiana
- French Polynesia
- Gabon
- Georgia
- Germany
- Ghana
- Gibraltar
- Greece
- Greenland
- Grenada
- Guadeloupe
- Guam
- Guatemala
- Guernsey
- Guinea
- Guinea-bissau
- Guyana
- Haiti
- Honduras
- Hong Kong
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Iraq

- Ireland
- Isle Of Man
- Israel
- Italy
- Ivory Coast
- Jamaica
- Japan
- Jersey
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Kosovo
- Kuwait
- Kyrgyzstan
- Laos
- Latvia
- Lebanon
- Lesotho
- Liberia
- Libya
- Liechtenstein
- Lithuania
- Luxembourg
- Macau
- Macedonia
- Madagascar
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania

- Mauritius
- Mayotte
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Namibia
- Nauru
- Nepal
- Netherlands
- New Caledonia
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norfolk Island
- North Korea
- Northern Ireland
- Northern Mariana Islands
- Norway
- Occupied Palestinian Territories
- Oman
- Pakistan
- Palau
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines

- Pitcairn, Henderson, Ducie And Oeno Islands
- Poland
- Portugal
- Puerto Rico
- Qatar
- Romania
- Russia
- Rwanda
- Réunion
- Saint Barthélemy
- Saint Helena
- Saint Pierre And Miquelon
- Saint Vincent
- Samoa
- San Marino
- Saudi Arabia
- Scotland
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Sint Maarten
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Georgia And South Sandwich Islands
- South Korea
- South Sudan
- Spain
- Sri Lanka
- St Kitts And Nevis
- St Lucia

- Sudan
- Suriname
- Svalbard And Jan Mayen
- Sweden
- Switzerland
- Syria
- São Tomé And Príncipe
- Taiwan
- Tajikistan
- Tanzania
- Thailand
- The Bahamas
- The Gambia
- Togo
- Tokelau
- Tonga
- Trinidad And Tobago
- Tunisia
- Turkey
- Turkmenistan
- Turks And Caicos Islands
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United States
- United States Virgin Islands
- Uruguay
- Uzbekistan
- Vanuatu
- Venezuela
- Vietnam
- Wallis And Futuna
- Yemen
- Zambia

- Zimbabwe
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-06-30	£1,077,604	£1,026,242	£337,879	27
2024-06-30	£965,218	£972,157	£286,517	27
2023-06-30	£949,226	£981,812	£293,456	26
2022-06-30	£892,298	£871,856	£326,042	25
2021-06-30	£731,979	£707,107	£305,600	24

Trustees

Name	Role	Appointed
Siriana Baldini	Chair	2024-09-06
Dr Rahul Raman Singh		2025-09-01
Emma Jane Hadfield-Hudson		2023-02-11
Gil Sarig		2024-01-04
Iraj Idafar		2022-02-06
LINDA CHRISTINE MILNE		2015-01-16
Nick James Leopold Shiroi		2024-04-16
Sharon Horth		2026-05-27
Sophia Walker		2026-05-27
Thomas Dalton		2024-05-12
Tulsi Sandys-Winsch		2023-10-11

Alex, The Leukodystrophy Charity

England & Wales - Charity number 1106008

Accounts

Charity registration number 1106008 (England and Wales)

Charity registration number SCO51539 (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 R Singh	(Appointed 6 September 2024) (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.

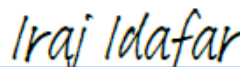
This report has been prepared in accordance with the special provisions of part 15 of Companies Act 2006 relating to small companies.

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	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
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		<u>862,383</u>	<u>102,835</u>	<u>965,218</u>
Expenditure on:				
Raising funds	7	698,956	-	698,956
Charitable activities	8	193,436	79,765	273,201
Total expenditure		<u>892,392</u>	<u>79,765</u>	<u>972,157</u>
Net income/(expenditure) and movement in funds		(30,009)	23,070	(6,939)
Reconciliation of funds:				
Fund balances at 1 July 2023		<u>234,105</u>	<u>59,351</u>	<u>293,456</u>
Fund balances at 30 June 2024		<u>204,096</u>	<u>82,421</u>	<u>286,517</u>

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			<u>310,659</u>		<u>268,604</u>
Total assets less current liabilities			<u>342,290</u>		<u>301,323</u>
Creditors: amounts falling due after more than one year	18		<u>(4,411)</u>		<u>(14,806)</u>
Net assets			<u><u>337,879</u></u>		<u><u>286,517</u></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)

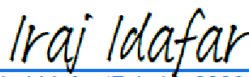
AS AT 30 JUNE 2025

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	
Net cash used in investing activities			(4,821)		(4,176)
Financing activities					
Repayment of bank loans		(10,139)		(9,889)	
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
Cash and cash equivalents at end of year			218,270		293,637

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
Analysis by fund						
Unrestricted funds	3,122	3,617	13,478	700	3,757	4,457
Restricted funds	-	-	-	-	280	280
	3,122	3,617	13,478	700	4,037	4,737

5 Income from other trading activities

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Fundraising events	7,815	24,886
Shop income	703,292	716,963
Other trading activities	711,107	741,849

6 Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Interest receivable	3,591	3,632

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/>	<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
	<u>92,492</u>	<u>53,669</u>	<u>38,347</u>	<u>79,252</u>	<u>263,760</u>
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
	<u>115,168</u>	<u>65,244</u>	<u>42,482</u>	<u>79,352</u>	<u>302,246</u>
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
	<u>115,168</u>	<u>65,244</u>	<u>42,482</u>	<u>79,352</u>	<u>302,246</u>

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
	<u>86,150</u>	<u>64,388</u>	<u>38,106</u>	<u>30,405</u>	<u>219,049</u>
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
	<u>114,358</u>	<u>84,408</u>	<u>44,030</u>	<u>30,405</u>	<u>273,201</u>
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
	<u>114,358</u>	<u>84,408</u>	<u>44,030</u>	<u>30,405</u>	<u>273,201</u>

9 Grants payable

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

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>21,440</u>	<u>21,308</u>

12 Employees

The average monthly number of employees during the year was:

	2025	2024
	Number	Number
	27	27
	<u>27</u>	<u>27</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
			<u>2,872</u>	<u>5,038</u>
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
			<u>152,907</u>	<u>98,572</u>
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
			<u>63,390</u>	<u>128,643</u>
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
			<u>4,411</u>	<u>14,806</u>

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

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)
	<u>201,986</u>	<u>135,893</u>	<u>337,879</u>

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>

Alex, The Leukodystrophy Charity

England & Wales - Charity number 1106008

Accounts

Charity registration number 1106008 (England and Wales)

Charity registration number SCO51539 (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 T Sandys-Winsch G Sarig T Dalton N Shiroi S Tan S Baldini	(Appointed 9 August 2023) (Appointed 11 October 2023) (Appointed 4 January 2024) (Appointed 12 May 2024) (Appointed 16 April 2024) (Appointed 2 May 2024) (Appointed 6 September 2024)
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 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 Leriglitzone, 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		<u>862,383</u>	<u>102,835</u>	<u>965,218</u>	<u>779,412</u>	<u>169,814</u>	<u>949,226</u>
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		<u>892,392</u>	<u>79,765</u>	<u>972,157</u>	<u>796,076</u>	<u>185,736</u>	<u>981,812</u>
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		<u>204,096</u>	<u>82,421</u>	<u>286,517</u>	<u>234,105</u>	<u>59,351</u>	<u>293,456</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

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			<u>293,637</u>		<u>288,452</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 2024 £	Awareness and Education 2024 £	Research 2024 £	Community Weekend 2024 £	Total 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
	<u>86,150</u>	<u>64,388</u>	<u>38,106</u>	<u>30,405</u>	<u>219,049</u>
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
	<u>114,358</u>	<u>84,408</u>	<u>44,030</u>	<u>30,405</u>	<u>273,201</u>
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
	<u>114,358</u>	<u>84,408</u>	<u>44,030</u>	<u>30,405</u>	<u>273,201</u>

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	Awareness and Education	Research	Community Weekend	Total
	2023	2023	2023	2023	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
	<u>78,052</u>	<u>56,490</u>	<u>17,719</u>	<u>112,254</u>	<u>264,515</u>
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
	<u>109,909</u>	<u>76,594</u>	<u>20,871</u>	<u>112,254</u>	<u>319,628</u>
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
	<u>109,909</u>	<u>76,594</u>	<u>20,871</u>	<u>112,254</u>	<u>319,628</u>

9 Grants payable

	Support Services 2024 £	Support Services 2023 £
Grants to individuals	1,085	3,009
	<u>1,085</u>	<u>3,009</u>

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)
	<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)
	<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>
		<u><u>98,572</u></u>	<u><u>45,964</u></u>
17 Creditors: amounts falling due within one year		2024	2023
		£	£
	Notes		
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>
		<u><u>128,643</u></u>	<u><u>54,051</u></u>
18 Creditors: amounts falling due after more than one year		2024	2023
		£	£
	Notes		
Bank loans	19	14,806	24,944
		<u>14,806</u>	<u>24,944</u>
		<u><u>14,806</u></u>	<u><u>24,944</u></u>
19 Loans and overdrafts		2024	2023
		£	£
Bank loans		24,946	34,835
		<u>24,946</u>	<u>34,835</u>
		<u><u>24,946</u></u>	<u><u>34,835</u></u>
		10,140	9,891
Payable within one year		10,140	9,891
Payable after one year		14,806	24,944
		<u>14,806</u>	<u>24,944</u>
		<u><u>14,806</u></u>	<u><u>24,944</u></u>
20 Retirement benefit schemes		2024	2023
		£	£
Defined contribution schemes			
Charge to profit or loss in respect of defined contribution schemes		12,961	10,995
		<u>12,961</u>	<u>10,995</u>
		<u><u>12,961</u></u>	<u><u>10,995</u></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	Resources 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>
Previous year:	At 1 July 2022	Incoming resources	Resources At 30 June 2023	
	£	£	£	£
	-	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	Resources At 30 June 2024	
	£	£	£	£
General funds	234,105	862,383	(892,392)	204,096
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
Previous year:	At 1 July 2022	Incoming resources	Resources At 30 June 2023	
	£	£	£	£
General funds	250,769	779,412	(796,076)	234,105
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

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)
	<u> </u>	<u> </u>	<u> </u>
	204,096	82,421	286,517
	<u> </u>	<u> </u>	<u> </u>

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>

Alex, The Leukodystrophy Charity

England & Wales - Charity number 1106008

Accounts

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 2023

ALEX, THE LEUKODYSTROPHY CHARITY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	L Milne G Bridge O Bostock T Watkins G Metcalf J Livingston I Idafar E Hadfield-Hudson K Amber T Sandys-Winsch G Sarig	(Appointed 11 February 2023) (Appointed 9 August 2023) (Appointed 11 October 2023) (Appointed 4 January 2024)
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 2023

The trustees present their annual report and financial statements for the year ended 30 June 2023.

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 have referred to the guidance in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives in planning its future activities. In particular, they have considered how planned activities will contribute to the aims and objectives they have set.

Achievements and performance

Organisation

Alex TLC continued to build on the growth experienced the previous year, taking on additional staff and activities, finalising projects, and cementing our position as the patient voice for the UK leukodystrophy community.

During the period we welcomed 121 new beneficiaries (an 8% increase year on year) with 11 different conditions, bringing the total number of conditions supported to 21 and delivered 1,353 support activities to 412 beneficiaries. Our community communications continued to strengthen with our newsletters achieving a 40% open rate, a year-on-year rise of 10%, and increased engagement across all social media channels. Website visits dropped year on year due to new regulations regarding cookies and consent.

We published our biennial 2022 Impact Report reflecting the views of 74 members of our community. The Report demonstrated that respondents continue to find Alex TLC their most important source of support, and that our services are relevant, professional, high quality and useful: "A life line for our family" "For a small charity, the support is excellent." "We would have been lost without (Alex TLC) ..."

Our Impact Report identified two priority areas for our community: research and concerns around mental health support. Alongside data trends from our new reporting structure this confirmed the need for additional support staff. As a result, we successfully applied for grants to employ a research analyst and a counsellor, with both posts filled early in 2023.

We launched a new research strategy in conjunction with the employment of our Research Analyst. Key elements included:

- monthly research summaries for our community in plain English, ensuring they are accessible and user-friendly
- partnership with Leukolabs, the UK's only research collaborative for leukodystrophies based in York University
- improved relationship building with key research organisations and pharmaceutical companies

Similarly, our BACP (British Association for Counselling and Psychotherapy) approved Counsellor was a welcome addition to the team with session spaces quickly filling up and positive feedback from those using the service – a survey reported that 100% had experienced improvements in how they felt they were coping with their/a loved one's leukodystrophy diagnosis.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

We held our first in person Community Weekend event since before Covid, and also our first event welcoming those affected by all leukodystrophies, bringing together 114 beneficiaries and 15 medical professionals and scientists for a weekend of information and presentations, peer support, condition management and relationship building activities. "I thought the event was brilliant. It was great to see so many individuals and families having the time to talk to others and learn from different professionals. Despite the challenges faced by many there, there was a real sense of positivity as people made connections and shared their stories." "We really loved attending. There was a great sense of community and shared warmth and care between everyone attending. A really positive event. Thank you." "The presentations and discussions amongst the health care professionals were very informative". Community Weekend Impact Report 2023.

Support for the event generated from our expanded portfolio of corporate stakeholders, alongside increased attendance numbers, confirmed our expanded remit to all leukodystrophy conditions has translated into increased opportunities for growth.

We took a strategic decision to move our online peer support network from Health Unlocked to a new Facebook group which encouraged increased membership and engagement.

We introduced quarterly Steering Group meetings to encourage engagement and ensure project development has a robust structure which demonstrates our commitment to community involvement and constructive use of community feedback.

We also introduced a monthly "Ask the Community" email where community members can ask for advice from peers, which has led to increased numbers of peer-to-peer connections.

We introduced small regional face to face events, holding two in the year, for a small number of beneficiaries to meet and enjoy a local attraction and lunch together, hosted by support staff. "I was anxious about going until I met the other families. I laughed all day until my cheeks hurt. I didn't want the day to end as I had finally found a new group of people just like me. I'm so happy to be a part of the Alex family and can't wait to see them all again.". Feedback from attendee.

We presented a poster at the British Paediatric Neurology Association highlighting our partnership with the NHS England Inherited White Matter Disorders Diagnostic and Management Service.

We represented patients in the working group proposing a change in NHS commissioning policy to allow adults with cerebral adrenoleukodystrophy (ALD) access to bone marrow transplant treatment, at the time only available to patients up to the age of 18.

Alex TLC joined the Eurordis Rare Neurological Disease European Reference Network as an ePAG (Patient Advocate Group) member, ensuring UK leukodystrophy patients are represented at European level, and that our resources and experiences are shared for the benefit of those outside the UK.

As part of our strategy to improve Search Engine Optimisation we undertook a full review of our current website, taking the decision to redesign the site to improve user journeys and optimise our online visibility. Our Steering Group has been regularly involved in development, and the project is due for completion in March 2024. The fundraising team developed new community and corporate fundraising guides packed with ideas and case studies to add to our suite of fundraising resources.

In response to our growth and higher numbers of staff, we engaged a new IT company to ensure our systems were up to date and secure. We initiated a Cyber insurance policy and also began the process of Cyber Essentials accreditation to demonstrate our commitment to digital security.

The retail business continued to improve and the overall contribution from our five charity shops was £77,399 (2022: £71,145), seeing an almost 9% increase year on year. Investment in additional fundraising staff resulted in an increase in donations and fundraising income to £100,707 (2022: £94,350), an increase of 7%. Grant income saw a substantial increase to £156,755 (2022: £65,902), an increase of 138%, largely due to funding secured for our Community Weekend event and our two new posts.

Due to the above substantial investment in our charitable objectives, the organisation saw a reduction in unrestricted reserves of £16,664 to £234,105.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

Charitable objectives

Across the year Alex TLC staff:

- welcomed 121 new beneficiaries, including 32 patients with ALD, 24 with other leukodystrophy conditions, 21 patients waiting for confirmation of their diagnosis, and 44 unaffected family members (such as parents, carers, siblings)
- delivered 1,353 support conversations including 146 home visits (in person and on zoom), 27 referrals and provision of advocacy at 30 professional meetings
- delivered 64 counselling sessions
- attracted 95 members to our new Facebook peer support group
- connected 56 members of our community together for peer support
- delivered 11 digital peer networking sessions to 51 beneficiaries
- granted £2,882 to beneficiaries in need
- presented at 20 events, including ALD Connect, Imperial London, Rare Disease Day Westminster event, London School of Paediatrics, United Leukodystrophy Foundation, Leukolabs
- attended 15 stakeholder conferences including Neurological Alliance, British Paediatric Neurology Association, Eurordis Members Meeting
- were involved in 250 stakeholder meetings including NHS England, Genetic Alliance, NICE, Medics for Rare Diseases, Rare Revolutions

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

NHS England Inherited White Matter Disorders (IWMD) Diagnostic and Management Service and Patient Registry –

The Service was mobilised during the period and support staff worked closely with clinic leads to provide patient support. Arrangements have been made for support staff to attend in-person clinics where possible, and Alex TLC literature has been distributed to all centres and used to encourage patients to access our support services. A link to Alex TLC's website has been included on all centre website pages, and we were asked to provide a dedicated page on the Alex TLC website for Service and Registry news. We continued to work closely on development of the Patient Registry, which is due for completion in 2024. Our partnership with the IWMD Service is also an integral element to our strategy to improve diversity within our Alex TLC community.

New Born Screening – In preparation for the review of our application to include ALD in the UK new born screening programme we held a New Born Screening Round Table event at our Community Weekend with eminent medical specialists from around the world. Our study with Sheffield Hallam University exploring the impact of childhood cerebral ALD on parents and carers was peer reviewed and recommended for publication by the journal *Child: health, care and development*. We also completed our scoping study with Genetic Alliance to confirm how adult males with ALD felt about new born screening, resulting in 100% positive reactions.

Support tools for children and young people – we launched our first support resource for Rare Disease Day (28th February 2023), “When My Brother Got Ill – A Story of Adrenoleukodystrophy (ALD)”, a fully illustrated story book to help young siblings of boys with Childhood Cerebral ALD understand a brother’s diagnosis and develop coping mechanisms. In the four months since publication 49 hard copies were ordered and 76 people viewed the online version. Feedback included “...this is very relatable to our family.” “It showed them it was ok to feel how they were feeling about the situation...”

Challenges

The cost of living crisis and increases in energy prices continued to be a major concern for future expenditure, alongside retention of our growing workforce. We continued to operate without a Chief Financial Officer, having been unable to recruit a suitable candidate. Although a support role was provided by the treasurer, this still significantly impacted on the workload of the Accounts Manager and Chief Executive Officer, diminishing capacity for income generation, particularly grant income.

We identified a lack of expertise to optimise opportunities for publicity through press and media outlets, as well as optimising social media reach and engagement.

Future

The growth experienced over the past two years has been welcomed by our community, but we now need to stabilise our workload and our finances in order to ensure future sustainability at these levels.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

We will continue to build and strengthen our stakeholder network, recognising the benefits this has brought in the past year and optimising our new Research Analyst role in our engagement with research and pharmaceutical organisations.

Following the success of our Community Weekend event, and feedback from patient and professional attendees, we will work towards holding this event annually.

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

Financial review

At the balance sheet date, the charity had unrestricted funds of £234,105 (2022: £250,769) and restricted funds of £59,351 (2022: £75,273).

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 do expect a further drop in reserves in 2023/24 as we invest further in our charitable activities.

Plans for future periods

Work areas for 2023/2024 include:

- confirmation of honorary contracts in order to provide in-person support for patients, families, and carers at NHSE IWMD clinics
- annual Community Weekend event
- launch our new website
- implement a strategy to cement our position as the umbrella organisation for leukodystrophies in the UK
- development of a sustainability policy

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.

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	
L Winn	(Resigned 11 February 2023)
O Bostock	
T Watkins	
S Jimenez	(Resigned 11 February 2024)
G Metcalf	
N Sarig	(Resigned 15 October 2023)
J Livingston	
I Idafar	
E Hadfield-Hudson	(Appointed 11 February 2023)
K Amber	(Appointed 9 August 2023)
T Sandys-Winsch	(Appointed 11 October 2023)
G Sarig	(Appointed 4 January 2024)

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

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, such as parents, 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.

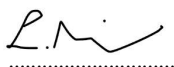
Risk

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. Currently our priority risk is appointment of a new Chair from September 2024 due to the end of the existing Chair's term. A Sub-Committee has been formed to implement an approved strategy for recruitment.

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

21/03/2024

Date:



Iraj Idafar(Mar 21, 2024 11:34 GMT)

.....
I Idafar

Trustee

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF TRUSTEES RESPONSIBILITIES

FOR THE YEAR ENDED 30 JUNE 2023

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 2023 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 2023 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

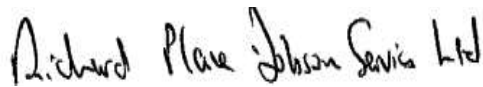
The audit engagement team identified the risk of management override of controls as the area where the financial statements were most susceptible to material misstatement due to fraud. Audit procedures performed included but were not limited to testing manual journal entries and other adjustments and 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

22 March 2024

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 2023

Current financial year

		Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Total 2022 £
	Notes				
<u>Income and endowments from:</u>					
Donations and grants	3	77,997	169,574	247,571	185,724
Other trading activities	4	697,726	-	697,726	702,602
Investments	5	1,537	-	1,537	57
Other income	6	2,152	240	2,392	3,915
Total income		<u>779,412</u>	<u>169,814</u>	<u>949,226</u>	<u>892,298</u>
<u>Expenditure on:</u>					
Raising funds	7	<u>662,184</u>	<u>-</u>	<u>662,184</u>	<u>658,658</u>
Charitable activities	8	<u>133,892</u>	<u>185,736</u>	<u>319,628</u>	<u>213,198</u>
Total expenditure		<u>796,076</u>	<u>185,736</u>	<u>981,812</u>	<u>871,856</u>
Net (expenditure)/income for the year/ Net movement in funds		(16,664)	(15,922)	(32,586)	20,442
Fund balances at 1 July 2022		<u>250,769</u>	<u>75,273</u>	<u>326,042</u>	<u>305,600</u>
Fund balances at 30 June 2023		<u><u>234,105</u></u>	<u><u>59,351</u></u>	<u><u>293,456</u></u>	<u><u>326,042</u></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 2023

Prior financial year

		Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
	Notes			
<u>Income and endowments from:</u>				
Donations and grants	3	98,140	87,584	185,724
Other trading activities	4	701,903	699	702,602
Investments	5	57	-	57
Other income	6	3,915	-	3,915
Total income		804,015	88,283	892,298
<u>Expenditure on:</u>				
Raising funds	7	658,175	483	658,658
Charitable activities	8	80,432	132,766	213,198
Total expenditure		738,607	133,249	871,856
Gross transfers between funds		3,231	(3,231)	-
Net (expenditure)/income for the year/ Net movement in funds		68,639	(48,197)	20,442
Fund balances at 1 July 2021		182,130	123,470	305,600
Fund balances at 30 June 2022		250,769	75,273	326,042

ALEX, THE LEUKODYSTROPHY CHARITY

BALANCE SHEET

AS AT 30 JUNE 2023

	Notes	2023 £	£	2022 £	£
Fixed assets					
Tangible assets	14		34,819		43,398
Current assets					
Stocks	15	3,217		3,877	
Debtors	16	45,963		66,011	
Cash at bank and in hand		288,452		285,634	
		<u>337,632</u>		<u>355,522</u>	
Creditors: amounts falling due within one year	18	<u>(54,051)</u>		<u>(38,045)</u>	
Net current assets			283,581		317,477
Total assets less current liabilities			318,400		360,875
Creditors: amounts falling due after more than one year	19		(24,944)		(34,833)
Net assets			<u>293,456</u>		<u>326,042</u>
Income funds					
Restricted funds	20		59,351		75,273
Unrestricted funds - general			234,105		250,769
			<u>293,456</u>		<u>326,042</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 2023, 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 21/03/2024



L Milne
Trustee


rajda6r(M ar 21, 2 024 11:34 GMT)

I Idafar
Trustee

Company registration number 05142341

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 30 JUNE 2023

	Notes	2023 £	£	2022 £	£
Cash flows from operating activities					
Cash generated from operations	24		12,200		18,480
Investing activities					
Purchase of tangible fixed assets		(1,274)		(40,885)	
Proceeds from disposal of tangible fixed assets		-		11,000	
Investment income received		1,537		57	
		<u>1,537</u>		<u>57</u>	
Net cash generated from/(used in) investing activities			263		(29,828)
Financing activities					
Repayment of bank loans		(9,645)		(5,520)	
		<u>(9,645)</u>		<u>(5,520)</u>	
Net cash used in financing activities			(9,645)		(5,520)
Net increase/(decrease) in cash and cash equivalents			2,818		(16,868)
Cash and cash equivalents at beginning of year			285,634		302,502
			<u>285,634</u>		<u>302,502</u>
Cash and cash equivalents at end of year			<u>288,452</u>		<u>285,634</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2023

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 £.

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 2023

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 & equipment	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 2023

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.

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 2023

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 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds general 2022 £	Restricted funds 2022 £	Total 2022 £
Donations and gifts	66,347	22,969	89,316	83,920	10,962	94,882
Grants received	11,650	146,605	158,255	14,220	76,622	90,842
	<u>77,997</u>	<u>169,574</u>	<u>247,571</u>	<u>98,140</u>	<u>87,584</u>	<u>185,724</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	10,000	-	10,000
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	-	-	-
Garfield Weston Foundation	-	-	-	-	15,000	15,000
FB Coales No 4	500	-	500	-	-	-
The Sylvia Aitken Charitable Trust	1,000	-	1,000	-	-	-
Arnold Clark Community Fund	-	-	-	2,000	-	-
The Anthony and Elizabeth Mellows Charitable Trust	2,500	-	-	-	-	-
London Catalyst Partners for Health	-	2,000	2,000	-	-	-
The Grace Trust	750	-	750	-	-	-
The National Lottery Community Funds	-	35,660	35,660	-	-	-
The Hospital Saturday Fund	-	2,000	2,000	-	-	-
Affinia Therapeutics	-	1,000	1,000	-	720	720

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

3 Donations and grants (Continued)

Autobahn Therapeutics	-	-	-	-	3,596	3,596
CAF The Rest-Harrow Trust	200	-	200	200	-	200
Ionis Pharmaceuticals	-	20,661	20,661	-	9,893	9,893
Leadiant Bioscience	-	-	-	-	2,500	2,500
Orchard Therapeutics	-	7,500	7,500	-	7,500	7,500
Passage Bio Inc	-	-	-	-	2,500	2,500
Poxel	-	1,000	1,000	-	728	728
Swanbio Therapeutics	-	5,000	5,000	-	3,611	3,611
The D'Oyly Carte Charitable Trust	-	-	-	-	4,000	4,000
The Edward Gostling Foundation	-	-	-	-	5,000	5,000
Vigil Neuroscience	-	11,816	11,816	-	11,574	11,574
Zedra Trust Comp Wo	-	-	-	-	5,000	5,000
Sylvia Adams CT	-	-	-	-	5,000	5,000
Lillie C Johnson Trust	-	-	-	500	-	500
Marsh Christian Trust	700	-	700	500	-	500
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	-	3,000	3,000	-	-	-
Viking Therapeutics	-	10,000	10,000	-	-	-
The Elsie Davis Trust	-	5,000	5,000	-	-	-
Forge Biologics	-	1,488	1,488	-	-	-
ASPA Therapeutics	-	4,988	4,988	-	-	-
BBC Children in Need	-	15,000	15,000	-	-	-
Other	-	-	-	520	-	520
	<u>11,650</u>	<u>146,605</u>	<u>158,255</u>	<u>14,220</u>	<u>76,622</u>	<u>90,842</u>

4 Other trading activities

	Unrestricted funds general 2023 £	Unrestricted funds general 2022 £	Restricted funds 2022 £	Total 2022 £
Fundraising income	28,135	-	-	-
Shop income	668,506	649,437	699	650,136
Shop income - government grants	1,085	52,466	-	52,466
Other trading activities	<u>697,726</u>	<u>701,903</u>	<u>699</u>	<u>702,602</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

5 Investments

	Unrestricted funds general 2023 £	Unrestricted funds general 2022 £
Interest receivable	1,537	57

6 Other income

	Unrestricted funds general 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds general 2022 £
Net gain on disposal of tangible fixed assets	-	-	-	3,915
Other income	2,152	240	2,392	-
	<u>2,152</u>	<u>240</u>	<u>2,392</u>	<u>3,915</u>

7 Raising funds

	Unrestricted funds general 2023 £	Unrestricted funds general 2022 £	Restricted funds 2022 £	Total 2022 £
<u>Fundraising and publicity</u>				
Other fundraising costs	21,154	10,578	-	10,578
Staff costs	48,837	28,980	-	28,980
	<u>69,991</u>	<u>39,558</u>	<u>-</u>	<u>39,558</u>
<u>Fundraising trading: costs of goods and other costs</u>				
Operating charity shops	190,355	241,287	483	241,770
Staff costs	392,777	369,187	-	369,187
Depreciation and impairment	9,061	8,143	-	8,143
	<u>592,193</u>	<u>618,617</u>	<u>483</u>	<u>619,100</u>
	<u>662,184</u>	<u>658,175</u>	<u>483</u>	<u>658,658</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

8 Charitable activities

	Support Services	Awareness and Education	Research	Community Weekend	Total 2023
	2023	2023	2023	2023	
	£	£	£	£	£
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 & maintenance	141	141	-	-	282
Bank Charges	6	-	1	-	7
	<u>78,052</u>	<u>56,490</u>	<u>17,719</u>	<u>112,254</u>	<u>264,515</u>
Grant funding of activities (see note 9)	3,009	-	-	-	3,009
Share of support costs (see note 10)	22,807	15,894	2,492	-	41,193
Share of governance costs (see note 10)	6,041	4,210	660	-	10,911
	<u>109,909</u>	<u>76,594</u>	<u>20,871</u>	<u>112,254</u>	<u>319,628</u>
Analysis by fund					
Unrestricted funds - general	61,148	69,395	3,348	1	133,892
Restricted funds	48,761	7,199	17,523	112,253	185,736
	<u>109,909</u>	<u>76,594</u>	<u>20,871</u>	<u>112,254</u>	<u>319,628</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

8 Charitable activities

(Continued)

For the year ended 30 June 2022

	Support Services	Awareness and Education	Research	Community Weekend	Total 2022
	£	£	£	£	£
Staff costs	63,428	22,806	1,401	13,847	101,482
Rates and water	1,792	1,792	-	-	3,584
Insurance	87	87	-	-	174
Light and heat	128	128	-	-	256
Telephone	229	183	-	-	412
Postage and stationery	361	121	-	-	482
Advertising	-	64	-	-	64
Consultancy fees	240	600	32,384	18,138	51,362
Conference costs	62	406	252	-	720
Travel costs	-	34	-	-	34
Subscriptions	599	250	29	-	878
Computer costs	1,266	1,298	114	154	2,832
Legal and professional	10	-	-	-	10
Staff training	97	97	-	-	194
Repairs & maintenance	1,159	1,159	-	-	2,318
Other charitable expenditure	69	-	-	574	643
	<u>69,527</u>	<u>29,025</u>	<u>34,180</u>	<u>32,713</u>	<u>165,445</u>
Grant funding of activities (see note 9)	2,405	-	-	-	2,405
Share of support costs (see note 10)	25,634	10,505	5,883	-	42,022
Share of governance costs (see note 10)	2,028	832	466	-	3,326
	<u>99,594</u>	<u>40,362</u>	<u>40,529</u>	<u>32,713</u>	<u>213,198</u>
Analysis by fund					
Unrestricted funds - general	43,332	30,502	6,598	-	80,432
Restricted funds	56,262	9,860	33,931	32,713	132,766
	<u>99,594</u>	<u>40,362</u>	<u>40,529</u>	<u>32,713</u>	<u>213,198</u>

9 Grants payable

	Support Services 2023 £	Support Services 2022 £
Grants to individuals	3,009	2,405
	<u>3,009</u>	<u>2,405</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

10 Support costs

	Support costs	Governance costs	2023 Support costs	Governance costs	2022
	£	£	£	£	£
Staff costs	26,410	-	26,410	23,199	23,199
Depreciation	785	-	785	508	508
Insurance	713	-	713	981	981
Telephone	354	-	354	196	196
Postage and stationery	337	-	337	742	742
IT Costs	3,646	-	3,646	3,257	3,257
Training and recruitment costs	823	-	823	4,370	4,370
Premises expenses	3,840	-	3,840	4,118	4,118
Repairs, maintenance and equipment	70	-	70	2,041	2,041
Subscriptions	260	-	260	411	411
Travel and subsistence	1,207	-	1,207	339	339
Sundry costs	333	-	333	-	-
Bank Charges	242	-	242	43	43
Bank Loan interest paid	1,003	-	1,003	1,211	1,211
Consultancy fee	1,170	-	1,170	606	606
Legal and professional	-	111	111	-	26
Accountancy fees	-	10,800	10,800	-	3,300
	<u>41,193</u>	<u>10,911</u>	<u>52,104</u>	<u>42,022</u>	<u>45,348</u>
Analysed between					
Charitable activities	<u>41,193</u>	<u>10,911</u>	<u>52,104</u>	<u>42,022</u>	<u>45,348</u>

Governance costs include amounts payable to the auditor of £10,800 (2022: £3,300 to the independent examiner) in respect of their audit.

11 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

12 Employees

The average monthly number of employees during the year was:

2023	2022
Number	Number
26	25
<u>26</u>	<u>25</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

12 Employees

(Continued)

Employment costs	2023 £	2022 £
Wages and salaries	520,869	482,801
Social security costs	38,158	30,934
Other pension costs	10,995	9,113
	<u>570,022</u>	<u>522,848</u>

Key Management Personnel

The trustees consider four (2022: four) staff members to be Key Management Personnel, the total benefit paid to them is £134,904 (2022: £126,335).

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

13 Taxation

The charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

14 Tangible fixed assets

	Plant and machinery £	Fixtures, fittings & equipment £	Motor vehicles £	Total £
Cost				
At 1 July 2022	31,384	13,200	36,964	81,548
Additions	1,274	-	-	1,274
Disposals	(245)	-	-	(245)
At 30 June 2023	<u>32,413</u>	<u>13,200</u>	<u>36,964</u>	<u>82,577</u>
Depreciation and impairment				
At 1 July 2022	26,066	6,600	5,492	38,158
Depreciation charged in the year	2,231	1,320	6,294	9,845
Eliminated in respect of disposals	(245)	-	-	(245)
At 30 June 2023	<u>28,052</u>	<u>7,920</u>	<u>11,786</u>	<u>47,758</u>
Carrying amount				
At 30 June 2023	<u>4,361</u>	<u>5,280</u>	<u>25,178</u>	<u>34,819</u>
At 30 June 2022	<u>5,326</u>	<u>6,600</u>	<u>31,472</u>	<u>43,398</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

15	Stocks		2023	2022
			£	£
	Consumables and branded goods		3,217	3,877
			<u> </u>	<u> </u>
16	Debtors		2023	2022
	Amounts falling due within one year:		£	£
	Trade debtors		2,738	4,795
	Other debtors		20,209	23,218
	Prepayments and accrued income		23,016	37,998
			<u> </u>	<u> </u>
			45,963	66,011
			<u> </u>	<u> </u>
17	Loans and overdrafts		2023	2022
			£	£
	Bank loans		34,835	44,480
			<u> </u>	<u> </u>
	Payable within one year		9,891	9,647
	Payable after one year		24,944	34,833
			<u> </u>	<u> </u>
18	Creditors: amounts falling due within one year		2023	2022
		Notes	£	£
	Bank loans	17	9,891	9,647
	Trade creditors		10,733	12,431
	Other creditors		12,429	12,214
	Accruals and deferred income		20,998	3,753
			<u> </u>	<u> </u>
			54,051	38,045
			<u> </u>	<u> </u>
19	Creditors: amounts falling due after more than one year		2023	2022
		Notes	£	£
	Bank loans	17	24,944	34,833
			<u> </u>	<u> </u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

20 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds				Balance at 30 June 2022 £
	Balance at 1 July 2021 £	Incoming resources £	Resource expended £	Transfer £	
Research	-	1,402	(1,402)	-	-
ScHARR Economic Survey	35,712	-	-	(35,712)	-
Education & Awareness	10,649	5,000	(5,847)	(7,291)	2,511
Family Weekend	1,120	31,594	(32,714)	-	-
Support Services	37,526	40,574	(57,051)	-	21,049
Technology	3,014	-	(482)	(2,532)	-
Core Costs	472	-	(472)	-	-
New Born Screening	33,777	-	(32,463)	35,712	37,026
Children's Support Tools	-	9,014	(2,818)	7,291	13,487
Covid Support Grant	-	699	-	(699)	-
Alexander's Disease	1,200	-	-	-	1,200
	<u>123,470</u>	<u>88,283</u>	<u>(133,249)</u>	<u>(3,231)</u>	<u>75,273</u>

	Movement in funds				Balance at 30 June 2023 £
	Balance at 1 July 2022 £	Incoming resources £	Resource expended £	Transfer £	
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>-</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.

ScHARR Economic Survey fund - Funding specifically reserved for a review of the economic survey commissioned for Alex TLC's original National Screening Committee application to add adrenoleukodystrophy to the UK new born screening programme.

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 2023

20 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.

Technology - A fund to purchase Gift Aid stock processing technology and optimise charity shop income generation. The tills purchased have been capitalised so a transfer has been put through to represent the fund being spent.

Core Costs - A pool of funds, generated through the emergency Covid-19 grants made available to the charity sector, to cover charitable core costs.

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

Covid Support Grant - a grant to support a pilot project exploring whether or not an online retail venture might be an additional profitable income stream.

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

21 Analysis of net assets between funds

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Fund balances at 30 June 2023 are represented by:						
Tangible assets	34,819	-	34,819	43,398	-	43,398
Current assets/(liabilities)	224,230	59,351	283,581	242,204	75,273	317,477
Long term liabilities	(24,944)	-	(24,944)	(34,833)	-	(34,833)
	<u>234,105</u>	<u>59,351</u>	<u>293,456</u>	<u>250,769</u>	<u>75,273</u>	<u>326,042</u>

22 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:

	2023 £	2022 £
Within one year	96,130	115,630
Between two and five years	163,884	326,790
In over five years	-	97,455
	<u>260,014</u>	<u>539,875</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2023

23 Related party transactions

There were no disclosable related party transactions during the year (2022 - Nil).

24 Cash generated from operations	2023 £	2022 £
(Deficit)/surplus for the year	(32,586)	20,442
Adjustments for:		
Investment income recognised in statement of financial activities	(1,537)	(57)
Gain on disposal of tangible fixed assets	-	(3,915)
Depreciation and impairment of tangible fixed assets	9,846	8,651
Movements in working capital:		
Decrease/(increase) in stocks	660	(3,206)
Decrease/(increase) in debtors	20,048	(5,966)
Increase in creditors	15,769	2,531
Cash generated from operations	12,200	18,480

25 Analysis of changes in net funds

	At 1 July 2022 £	Cash flows £	At 30 June 2023 £
Cash at bank and in hand	285,634	2,818	288,452
Loans falling due within one year	(9,647)	(244)	(9,891)
Loans falling due after more than one year	(34,833)	9,889	(24,944)
	<u>241,154</u>	<u>12,463</u>	<u>253,617</u>

Alex, The Leukodystrophy Charity

England & Wales - Charity number 1106008

Accounts

Charity registration number 1106008

Company registration number 05142341 (England and Wales)

ALEX, THE LEUKODYSTROPHY CHARITY
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

ALEX, THE LEUKODYSTROPHY CHARITY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	L Milne G Bridge O Bostock T Watkins S Jimenez G Metcalf N Sarig J Livingston I Idafar E Hadfield-Hudson	(Appointed 15 May 2022) (Appointed 6 February 2022) (Appointed 11 February 2023)
Secretary	Sara Hunt	
Charity number	1106008	
Company number	05142341	
Registered office	45 Peckham High Street London SE15 5EB	
Independent examiner	Darren Harding ACA FCCA DChA Richard Place Dobson Services Limited 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 2022

The trustees present their annual report and financial statements for the year ended 30 June 2022.

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 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:

- relief of sickness of people with Adrenoleukodystrophy (ALD), Adrenomyeloneuropathy (AMN) and other leukodystrophies and their parents and carers;
- to promote medical research into Adrenoleukodystrophy, Adrenomyeloneuropathy and other leukodystrophies and the publication of useful results of such research for the benefit of the public;
- to advance the education of the public in Adrenoleukodystrophy, Adrenomyeloneuropathy and other leukodystrophies.

The trustees have referred to the guidance in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives in planning its future activities. In particular, they have considered how planned activities will contribute to the aims and objectives they have set.

Achievements and performance

Organisation

Despite the income challenges experienced as a whole by the sector, Alex TLC experienced significant growth during the period, and took on additional charitable activities and projects.

As part of this growth, we prioritised promoting our work, publishing our 2022 Impact Report. It also seemed prudent to publicly reflect our national status and we registered with the Office of the Scottish Charity Regulator.

Following on from the previous year, we used the data and experiences collected to review internal processes and staff structure. We introduced a new reporting framework including regular departmental and team meetings with a full review of our Key Performance Indicators. These have resulted in providing the Charity with a clearer pathway for identifying successes and areas of risk. We also introduced a new salary framework and performance-related bonus scheme and engaged the services of an experienced HR consultant to meet the needs of our growing workforce.

Although the retail business experienced several premise-related challenges resulting in closure of one premises for three months, this was countered by overall increases in retail income, helped by the grants and additional staff available from the Kickstart initiative and successful insurance claims. Overall contribution from the shops was £71,145 for the year, compared with £41,886 for 2021 when they were still struggling with the Covid restrictions. Voluntary donations increased significantly in the year to £94,350 (2021: £30,424) but grant income was disappointing at £91,374, compared to £180,581 in the 2021 year. This reflects the increased competition for increasingly scarce resources within the charity sector. However, overall, our reserve levels grew with reduced expenditure mitigating the loss of grant income.

As part of our investment in future growth, we decided to invest heavily in fundraising staff, employing a Fundraising Manager and Fundraising Assistant to implement a revised fundraising strategy including recruitment of a team of voluntary grant fundraisers. We also invested in consultancy services for larger grant bids, which we hope to see realised in the next financial year. We employed additional staff to the retail team, following successful use of the government Kickstart Scheme, and purchased an additional Gift Aid till. The Chief Financial Officer position remained vacant due to a continued national shortage of available candidates. To support the Accounts Manager and increase capacity for administrative tasks, we also employed an Accounts and Administration Assistant.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

Our priorities for the period continued to be ensuring that anyone with a leukodystrophy who needs us can find us and widening our reach. With this in mind, we have continued investing in digital marketing consultancy resulting in improved Search Engine Optimisation, continuous assessment of our website and use of social media, alongside trials of paid social media advertising. Audience levels and engagement were closely monitored within our new KPI framework, and we anticipated and reacted to opportunities swiftly. We also engaged a digital marketing volunteer to promote the retail business and maintain our LinkedIn account.

We continued to work with NHS England as the lead patient and public voice (PPV) representative for the Inherited White Matter Disorder Diagnosis and Management Service and accompanying clinical registry; and were invited to be involved in the review of the adult bone marrow transplant policy for adrenoleukodystrophy (ALD).

We progressed our campaign to include ALD in the UK new born screening programme, and collaborated with new peer, research and pharmaceutical organisations to increase our stakeholder network, becoming more involved with stakeholders interested in rarer conditions such as Alexander's Disease and ALSP.

We maintained our involvement in the Lysosomal Storage Disorders Collaborative, New Born Screening Collaborative, Genetic Alliance Trustee Board, and joined the Neurological Alliance.

We were able to incorporate the Beneficiary Engagement Officer role within core provision and changed the job title to Engagement and Communications Officer. Staff and our community welcomed the return of our grant programme and in person home visits, although Zoom home visits have been maintained as a permanent feature.

During the period we welcomed 112 new beneficiaries (a 45% increase year on year), seeing a distinct increase in the numbers of new beneficiaries affected by conditions other than ALD (50% affected by ALD, 50% by other leukodystrophies), demonstrating that our investment in SEO consultancy was delivering real impact. We delivered 1,533 support conversations to 398 beneficiaries, demonstrating a 73% year on year increase. In terms of engagement and communications, we introduced a new format newsletter and, in recognition of our community's desire for more research-related activities (our 2020 Impact Report respondents placed research as a priority in communications from Alex TLC), we introduced monthly research summaries in August 2021. A new communication strategy gave us a solid baseline for the new KPI framework, with significant spikes during activities such as Leukodystrophy Awareness month, Rare Disease Day and Alex TLC campaigns and activities.

These figures also clearly demonstrated the increased workload of our support and engagement team. As a result, we submitted several grant applications to recruit a Research Analyst and Counsellor (areas of need identified in our 2022 Impact Report as well as through our KPI framework).

CHARITABLE OBJECTIVES

Across the year Alex TLC staff:

- welcomed 112 new beneficiaries, including 33 patients with ALD, 33 with other leukodystrophy conditions, 20 patients waiting for confirmation of their diagnosis, and 26 unaffected family members (such as parents, carers, siblings)
- delivered 1,533 support conversations including 118 home visits, 19 referrals and provision of advocacy at 32 professional meetings
- granted £2,200 to beneficiaries in need
- presented at 15 events, including the Leukodystrophy Professionals Meeting, Royal College of General Practitioners, British Paediatric Neurology Association and Medics4Rare Disease
- attended 29 stakeholder conferences including Genomics England, Westminster Health Forum Rare Disease Framework, Rare Disease Showcase, International Society for Neonatal Screening
- were involved in 288 stakeholder meetings including NHS England, National Screening Committee, CEREBRA, Genetic Alliance

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

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

NHS England Inherited White Matter Disorders (IWMD) Diagnostic and Management Service and Patient Registry – Further delays impacted roll out of this hugely important patient service, which is now scheduled for roll out in 2023. We became increasingly involved, developing our relationships with the commissioners, consultants and medical professionals delivering the project. As part of this partnership, we were invited to sit on the NHS service provider selection panel, and tasked with co-production of the patient information and registry pilot surveys with our PPV associates Metabolic Support UK. We were also recruited to the planning committee for mobilisation of the service including arrangements for Alex TLC staff to provide support at clinics. We moved our project to improve engagement with under-represented communities to this workstream having identified that working with the service will give the best opportunities for improvement and continue to work in partnership with service providers to develop appropriate resources.

New Born screening – In preparation for the 2023/24 review of our application to include ALD in the UK new born screening programme we held a digital New Born Screening Round Table event with eminent medical specialists from around the world. We also commissioned Sheffield Hallam University to publish a paper exploring the impact of childhood cerebral ALD on parents and carers. We also worked with Genetic Alliance to conduct a scoping study to confirm how adult males with ALD felt about new born screening. We continue to work with the New Born Screening Collaborative to highlight mutual concerns in the National Screening Committee's assessment processes.

Support tools for children and young people – First drafts of a fully illustrated children's book, designed to help parents and children up to 12 years old discuss and understand the implications of a sibling's ALD diagnosis, were shared with our Steering Group. This will provide a template for a series of books focussed on other leukodystrophies and beneficiary cohorts.

Digital Support Services and Community Weekend 2021 – The impact of the relaxation of Covid restrictions was reflected in reduced visits (773, a 52% year on year reduction) to our Covid information page, which we continue to update. We delivered 17 digital support activities to 41 beneficiaries, which was similar to the previous period, however there was a definitive drop off towards the end of the reporting period demonstrating a decline in appetite. As a result, activities were reduced to one per month.

We held our 2021 Digital Community Weekend in November, funded by existing and new corporate stakeholders. Attendance was down on the previous year, yet the Impact Report showed how valued the event was for our community "Thank you for keeping us connected to developments in this terrible condition", "Thank you to Alex TLC for putting together an excellent weekend". Recorded presentations were viewed by 361 individuals on our YouTube channel.

Genetic counselling – We published the results of our project with an MSc Student in Genetic and Genomic Counselling to explore family communication following an ALD diagnosis within the UK. The study outlined the variety of challenges families faced in communicating a diagnosis to wider family members and has been used to communicate a new service to assist beneficiaries to talk to relatives about the genetic implications of a leukodystrophy diagnosis.

CHALLENGES

The cost-of-living crisis and increases in energy prices are a major concern for future expenditure, alongside retention of our growing workforce. We continued to operate without a Chief Financial Officer, having been unable to recruit a suitable candidate. Although a support role was provided by the treasurer, this still significantly impacted on the workload of the Accounts Manager and Chief Executive Officer, diminishing capacity for income generation, particularly grant income.

Three of our retail premises incurred major damages due to extreme weather and longstanding defects, with insurance claims and reimbursements not fully materialised during the reporting period.

We noted a decline in engagement within our peer support network, demonstrating a need to review and assess community involvement.

We identified a lack of expertise to optimise opportunities for publicity through press and media outlets.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

FUTURE

We will look to increase staffing levels in order to input more meaningfully into research activities and provide additional mental health support for our community.

We will focus work priorities toward research and peer support.

We will continue to build and strengthen our stakeholder network, increasing our portfolio of corporate support and involvement with research organisations and collaboratives, recognising the benefits these bring for both our organisation and the leukodystrophy community.

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

Financial review

At the balance sheet date, the charity had unrestricted funds of £250,769 (2021: £182,130) and restricted funds of £75,273 (2021: £123,470).

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 (£220,000). Thanks to strict budget controls and generous allowances, our reserve levels are now above this minimum level. However, increases in the cost of living, increased competition for grant funding and a growing portfolio of charitable activities are at risk of impacting levels severely for the next period.

FUTURE PLANS

Work areas for 2022/2023 include:

- provision of in person support for patients, families and carers at NHSE IWMD clinics
- a return to face-to-face activities including localised beneficiary events and an in person Community Weekend
- publication of our research study with Sheffield Hallam University to explore the impact of a cerebral adrenoleukodystrophy diagnosis for parents and carers which will strengthen our campaign to add ALD to the UK new born screening programme
- successfully influence an NHS policy to allow adults to access bone marrow transplant to treat adult cerebral ALD
- recruit a Counsellor
- recruit a Research Analyst
- publish our children's book to support siblings of boys with cerebral ALD
- redesign our website to optimise the user journey and our digital presence
- improve engagement and activities related to our peer support network

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.

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

N Long

(Resigned 7 February 2022)

G Bridge

L Winn

(Resigned 11 February 2023)

O Bostock

T Watkins

S Jimenez

G Metcalf

N Sarig

J Livingston

(Appointed 15 May 2022)

I Idafar

(Appointed 6 February 2022)

E Hadfield-Hudson

(Appointed 11 February 2023)

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

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, such as parents, 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.

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 trustees report was approved by the Board of Trustees.

.....

L Milne
Trustee

Dated:

.....

S Jimenez
Trustee

Dated:

ALEX, THE LEUKODYSTROPHY CHARITY

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF ALEX, THE LEUKODYSTROPHY CHARITY

I report to the trustees on my examination of the financial statements of Alex, The Leukodystrophy Charity (the charity) for the year ended 30 June 2022.

Responsibilities and basis of report

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

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

Independent examiner's statement

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the ICAEW, which is one of the listed bodies.

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

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

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

Darren Harding ACA FCCA DChA

Richard Place Dobson Services Limited
1-7 Station Road
Crawley
West Sussex
RH10 1HT

Dated:

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 JUNE 2022

		Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
	Notes						
<u>Income and endowments from:</u>							
Donations and grants	3	98,140	87,584	185,724	24,512	225,206	249,718
Other trading activities	4	701,903	699	702,602	482,238	-	482,238
Investments	5	57	-	57	23	-	23
Other income	6	3,915	-	3,915	-	-	-
Total income		804,015	88,283	892,298	506,773	225,206	731,979
<u>Expenditure on:</u>							
Raising funds	7	658,175	483	658,658	439,116	76,048	515,164
Charitable activities	8	80,432	132,766	213,198	16,354	175,589	191,943
Total expenditure		738,607	133,249	871,856	455,470	251,637	707,107
Net incoming/(outgoing) resources before transfers		65,408	(44,966)	20,442	51,303	(26,431)	24,872
Gross transfers between funds		3,231	(3,231)	-	4,683	(4,683)	-
Net income/(expenditure) for the year/ Net movement in funds		68,639	(48,197)	20,442	55,986	(31,114)	24,872
Fund balances at 1 July 2021		182,130	123,470	305,600	126,144	154,584	280,728
Fund balances at 30 June 2022		250,769	75,273	326,042	182,130	123,470	305,600

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 2022

	Notes	2022 £	£	2021 £	£
Fixed assets					
Tangible assets	13		43,398		18,248
Current assets					
Stocks	14	3,877		671	
Debtors	15	66,011		60,045	
Cash at bank and in hand		285,634		302,502	
		<u>355,522</u>		<u>363,218</u>	
Creditors: amounts falling due within one year	17	<u>(38,045)</u>		<u>(31,383)</u>	
Net current assets			317,477		331,835
Total assets less current liabilities			360,875		350,083
Creditors: amounts falling due after more than one year	18		(34,833)		(44,483)
Net assets			<u>326,042</u>		<u>305,600</u>
Income funds					
Restricted funds	20		75,273		123,470
Unrestricted funds - general			250,769		182,130
			<u>326,042</u>		<u>305,600</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 2022.

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 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

.....
S Jimenez
Trustee

Company registration number 05142341

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 30 JUNE 2022

	Notes	2022 £	£	2021 £	£
Cash flows from operating activities					
Cash generated from operations	23		18,480		53,644
Investing activities					
Purchase of tangible fixed assets		(40,885)		(1,383)	
Proceeds on disposal of tangible fixed assets		11,000		-	
Investment income received		57		23	
		<u> </u>		<u> </u>	
Net cash used in investing activities			(29,828)		(1,360)
Financing activities					
New bank loans		(5,520)		50,000	
Payment of obligations under finance leases		-		(7,600)	
		<u> </u>		<u> </u>	
Net cash (used in)/generated from financing activities			(5,520)		42,400
Net (decrease)/increase in cash and cash equivalents			(16,868)		94,684
Cash and cash equivalents at beginning of year			302,502		207,818
Cash and cash equivalents at end of year			<u>285,634</u>		<u>302,502</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2022

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 of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

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 £.

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 2022

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 & equipment	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 2022

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.

Net realisable value is the estimated selling price less all estimated costs of completion and costs to be incurred in marketing, selling and distribution.

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.

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.

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.

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

2 Critical accounting estimates and judgements

(Continued)

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 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds general 2021 £	Restricted funds 2021 £	Total 2021 £
Donations and gifts	83,920	10,962	94,882	23,512	6,912	30,424
Grants received	14,220	76,622	90,842	1,000	218,294	219,294
	<u>98,140</u>	<u>87,584</u>	<u>185,724</u>	<u>24,512</u>	<u>225,206</u>	<u>249,718</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

3 Donations and grants

(Continued)

Grants receivable for core activities

Postcode Neighbour	-	-	-	-	20,000	20,000
BBC Children in Need	-	-	-	-	13,166	13,166
Minoryx Therapeutics	10,000	-	10,000	-	8,000	8,000
CAF	-	-	-	-	39,465	39,465
Contact a Family	-	-	-	-	25,000	25,000
National Lottery	-	-	-	-	10,000	10,000
The Hobson Charity	-	-	-	-	1,000	1,000
Garfield Weston Foundation	-	15,000	15,000	-	15,000	15,000
Global MSN	-	-	-	-	25,000	25,000
INTERESBA Sarigs Discretion	-	-	-	-	1,000	1,000
Arnold Clark Community Fund	2,000	-	2,000	-	-	-
Social Entrepreneur Support Fund	-	-	-	-	38,713	38,713
The Baily Thomas	-	-	-	-	20,000	20,000
The Grace Trust	-	-	-	1,000	-	1,000
The Sir Jules Thorn Charitable Trust	-	-	-	-	1,000	1,000
The Thomas Sivewright Catto Charitable Trust	-	-	-	-	750	750
Affinia Therapeutics	-	720	720	-	-	-
Autobahn Therapeutics	-	3,596	3,596	-	-	-
CAF The Rest-Harrow Trust	200	-	200	-	-	-
Ionis Pharmaceuticals	-	9,893	9,893	-	-	-
Leadiant Bioscience	-	2,500	2,500	-	-	-
Orchard Therapeutics	-	7,500	7,500	-	-	-
Passage Bio Inc	-	2,500	2,500	-	-	-
Poxel	-	728	728	-	-	-
Swanbio Therapeutics	-	3,611	3,611	-	-	-
The D'Oyly Carte Charitable Trust	-	4,000	4,000	-	-	-
The Edward Gostling Foundation	-	5,000	5,000	-	-	-
Vigil Neuroscience	-	11,574	11,574	-	-	-
Zedra Trust Comp Wo	-	5,000	5,000	-	-	-
Sylvia Adams CT	-	5,000	5,000	-	-	-
Lillie C Johnson Trust	500	-	500	-	-	-
Marsh Christian Trust	500	-	500	-	-	-
The Michael and Anna Wix Charitable Trust	500	-	500	-	200	200
Other	520	-	520	-	-	-
	<u>14,220</u>	<u>76,622</u>	<u>90,842</u>	<u>1,000</u>	<u>218,294</u>	<u>219,294</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

4 Other trading activities

	Unrestricted funds general 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds general 2021 £
Shop income	649,437	699	650,136	270,559
Shop income - government grants	52,466		52,466	211,679
	<u>701,903</u>	<u>699</u>	<u>702,602</u>	<u>482,238</u>

5 Investments

	Unrestricted funds general 2022 £	Unrestricted funds general 2021 £
Interest receivable	57	23
	<u>57</u>	<u>23</u>

6 Other income

	Unrestricted funds general 2022 £	Total 2021 £
Net gain on disposal of tangible fixed assets	3,915	-
	<u>3,915</u>	<u>-</u>

7 Raising funds

	Unrestricted funds general 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds general 2021 £	Restricted funds 2021 £	Total 2021 £
<u>Fundraising and publicity</u>						
Other fundraising costs	10,578	-	10,578	5,919	1,725	7,644
Staff costs	28,980	-	28,980	1,203	36,607	37,810
	<u>39,558</u>	<u>-</u>	<u>39,558</u>	<u>7,122</u>	<u>38,332</u>	<u>45,454</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

7 Raising funds (Continued)

Fundraising trading: costs
of goods and other costs

Operating charity shops	241,287	483	241,770	141,766	14,874	156,640
Staff costs	369,187	-	369,187	284,197	22,842	307,039
Depreciation and impairment	8,143	-	8,143	6,031	-	6,031
Fundraising trading: costs of goods and other costs	618,617	483	619,100	431,994	37,716	469,710
	658,175	483	658,658	439,116	76,048	515,164

8 Charitable activities

	Support Services	Awareness and Education	Research	Community Weekend	Total 2022	Total 2021
	2022	2022	2022	2022		
	£	£	£	£	£	£
Staff costs	63,428	22,806	1,401	13,847	101,482	89,065
Rates and water	1,792	1,792	-	-	3,584	4,174
Insurance	87	87	-	-	174	306
Light and heat	128	128	-	-	256	271
Telephone	229	183	-	-	412	526
Postage and stationery	361	121	-	-	482	57
Advertising	-	64	-	-	64	590
Community Weekend	-	-	-	-	-	4,159
Consultancy fees	240	600	32,384	18,138	51,362	14,777
Conference costs	62	406	252	-	720	38
Travel costs	-	34	-	-	34	-
Subscriptions	599	250	29	-	878	664
Computer costs	1,266	1,298	114	154	2,832	4,824
Legal and professional	10	-	-	-	10	151
Staff training	97	97	-	-	194	315
Repairs & maintenance	1,159	1,159	-	-	2,318	444
Other charitable expenditure	69	-	-	574	643	29
	69,527	29,025	34,180	32,713	165,445	120,390

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

8 Charitable activities	(Continued)					
Grant funding of activities (see note 9)	2,405	-	-	-	2,405	1,500
Share of support costs (see note 10)	25,634	10,505	5,883	-	42,022	66,950
Share of governance costs (see note 10)	2,028	832	466	-	3,326	3,103
	<u>99,594</u>	<u>40,362</u>	<u>40,529</u>	<u>32,713</u>	<u>213,198</u>	<u>191,943</u>
Analysis by fund						
Unrestricted funds - general	43,332	30,502	6,598	-	80,432	16,354
Restricted funds	56,262	9,860	33,931	32,713	132,766	175,589
	<u>99,594</u>	<u>40,362</u>	<u>40,529</u>	<u>32,713</u>	<u>213,198</u>	<u>191,943</u>

For the year ended 30 June 2021

	Support Services	Awareness and Education	Research	Community Weekend	Total 2021
	£	£	£	£	£
Staff costs	51,367	26,593	1,444	9,661	89,065
Rates and water	2,087	2,087	-	-	4,174
Insurance	153	153	-	-	306
Light and heat	135	136	-	-	271
Telephone	384	142	-	-	526
Postage and stationery	30	27	-	-	57
Advertising	-	519	71	-	590
Community Weekend	387	-	-	3,772	4,159
Consultancy fees	1,175	3,000	-	10,602	14,777
Conference costs	38	-	-	-	38
Subscriptions	548	-	116	-	664
Computer costs	3,070	1,704	50	-	4,824
Legal and professional	151	-	-	-	151
Staff training	315	-	-	-	315
Repairs & maintenance	222	222	-	-	444
Other charitable expenditure	28	-	1	-	29
	<u>60,090</u>	<u>34,583</u>	<u>1,682</u>	<u>24,035</u>	<u>120,390</u>
Grant funding of activities (see note 9)	1,500	-	-	-	1,500
Share of support costs (see note 10)	42,180	23,432	1,338	-	66,950
Share of governance costs (see note 10)	1,955	1,086	62	-	3,103
	<u>105,725</u>	<u>59,101</u>	<u>3,082</u>	<u>24,035</u>	<u>191,943</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

8 Charitable activities

(Continued)

Analysis by fund

Unrestricted funds - general	11,186	4,959	209	-	16,354
Restricted funds	94,539	54,142	2,873	24,035	175,589
	<u>105,725</u>	<u>59,101</u>	<u>3,082</u>	<u>24,035</u>	<u>191,943</u>

9 Grants payable

	Support Services 2022 £	Support Services 2021 £
Grants to individuals	2,405	1,500
	<u>2,405</u>	<u>1,500</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

10 Support costs

	Support costs	Governance costs	2022 Support costs	Governance costs	2021
	£	£	£	£	£
Staff costs	23,199	-	23,199	51,294	51,294
Depreciation	508	-	508	1,468	1,468
Insurance	981	-	981	1,006	1,006
Telephone	196	-	196	371	371
Postage and stationery	742	-	742	63	63
IT Costs	3,257	-	3,257	6,042	6,042
Training and recruitment costs	4,370	-	4,370	1,251	1,251
Premises expenses	4,118	-	4,118	4,820	4,820
Repairs, maintenance and equipment	2,041	-	2,041	66	66
Subscriptions	411	-	411	249	249
Travel and subsistence	339	-	339	129	129
Sundry costs	-	-	-	191	191
Bank Charges	43	-	43	-	-
Bank Loan interest paid	1,211	-	1,211	-	-
Consultancy fee	606	-	606	-	-
Legal and professional	-	26	26	-	13
Accountancy fees	-	3,300	3,300	-	3,000
Other governance costs	-	-	-	-	90
	<u>42,022</u>	<u>3,326</u>	<u>45,348</u>	<u>66,950</u>	<u>70,053</u>
Analysed between					
Charitable activities	<u>42,022</u>	<u>3,326</u>	<u>45,348</u>	<u>66,950</u>	<u>70,053</u>

Governance costs include amounts payable to the independent examiner of £3,300 (2021: £3,000) in respect of their independent examination.

11 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

12 Employees

The average monthly number of employees during the year was:

2022	2021
Number	Number
25	24
<u>25</u>	<u>24</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

12 Employees (Continued)

Employment costs	2022 £	2021 £
Wages and salaries	482,801	447,727
Social security costs	30,934	28,747
Other pension costs	9,113	8,734
	<u>522,848</u>	<u>485,208</u>

Key Management Personnel

The trustees consider four (2021: four) staff members to be Key Management Personnel, the total benefit paid to them is £126,335 (2021: £117,581).

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

13 Tangible fixed assets

	Plant and Fixtures, fittings machinery & equipment £	& equipment £	Motor vehicles £	Total £
Cost				
At 1 July 2021	27,464	13,200	27,025	67,689
Additions	3,921	-	36,964	40,885
Disposals	-	-	(27,025)	(27,025)
	<u>31,385</u>	<u>13,200</u>	<u>36,964</u>	<u>81,549</u>
At 30 June 2022				
At 1 July 2021	24,220	5,280	19,940	49,440
Depreciation charged in the year	1,839	1,320	5,492	8,651
Eliminated in respect of disposals	-	-	(19,940)	(19,940)
	<u>26,059</u>	<u>6,600</u>	<u>5,492</u>	<u>38,151</u>
At 30 June 2022				
Carrying amount				
At 30 June 2022	<u>5,326</u>	<u>6,600</u>	<u>31,472</u>	<u>43,398</u>
At 30 June 2021	<u>3,243</u>	<u>7,920</u>	<u>7,085</u>	<u>18,248</u>

14 Stocks

	2022 £	2021 £
Finished goods and goods for resale	<u>3,877</u>	<u>671</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

15 Debtors

	2022	2021
	£	£
Amounts falling due within one year:		
Trade debtors	4,795	3,219
Other debtors	23,218	37,163
Prepayments and accrued income	37,998	19,663
	<u>66,011</u>	<u>60,045</u>

16 Loans and overdrafts

	2022	2021
	£	£
Bank loans	<u>44,480</u>	<u>50,000</u>
Payable within one year	9,647	5,517
Payable after one year	<u>34,833</u>	<u>44,483</u>

17 Creditors: amounts falling due within one year

	Notes	2022	2021
		£	£
Bank loans	16	9,647	5,517
Trade creditors		12,431	10,929
Other creditors		12,214	11,522
Accruals and deferred income		3,753	3,415
		<u>38,045</u>	<u>31,383</u>

18 Creditors: amounts falling due after more than one year

	Notes	2022	2021
		£	£
Bank loans	16	<u>34,833</u>	<u>44,483</u>

19 Retirement benefit schemes

Defined contribution 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.

The charge to profit or loss in respect of defined contribution schemes was £9,113 (2021 - £8,734).

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

20 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds				Movement in funds				Balance at 30 June 2022 £
	Balance at 1 July 2020 £	Incoming resources £	Resource expended £	Transfer £	Balance at 1 July 2021 £	Incoming resources £	Resource expended £	Transfer £	
Research	500	-	(500)	-	-	1,402	(1,402)	-	-
ScHARR Economic Survey	35,712	-	-	-	35,712	-	-	(35,712)	-
Education & Awareness	10,950	10,000	(10,301)	-	10,649	5,000	(5,847)	(7,291)	2,511
Family Weekend	24,355	(1,342)	(21,893)	-	1,120	31,594	(32,714)	-	-
Support Services	42,603	60,000	(64,367)	(710)	37,526	40,574	(57,051)	-	21,049
Technology	3,014	-	-	-	3,014	-	(482)	(2,532)	-
Digital Support Costs	10,512	-	(10,512)	-	-	-	-	-	-
Core Costs	6,938	97,587	(103,380)	(673)	472	-	(472)	-	-
New Born Screening	20,000	19,048	(5,271)	-	33,777	-	(32,463)	35,712	37,026
Children's Support Tools	-	-	-	-	-	9,014	(2,818)	7,291	13,487
Covid Support Grant	-	38,713	(35,413)	(3,300)	-	699	-	(699)	-
Alexander's Disease	-	1,200	-	-	1,200	-	-	-	1,200
	<u>154,584</u>	<u>225,206</u>	<u>(251,637)</u>	<u>(4,683)</u>	<u>123,470</u>	<u>88,283</u>	<u>(133,249)</u>	<u>(3,231)</u>	<u>75,273</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

20 Restricted funds

(Continued)

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

ScHARR Economic Survey fund - Funding specifically reserved for a review of the economic survey commissioned for Alex TLC's original National Screening Committee application to add adrenoleukodystrophy to the UK new born screening programme.

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.

Community Weekend fund – organisation of a service user 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.

Technology - A fund to purchase Gift Aid stock processing technology and optimise charity shop income generation. The tills purchased have been capitalised so a transfer has been put through to represent the fund being spent.

Digital Support Costs - A fund for work undertaken to implement conversion of relevant Alex TLC activities to a digital format as part of our Covid-19 response strategy.

Core Costs - A pool of funds, generated through the emergency Covid-19 grants made available to the charity sector, to cover charitable core costs.

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

Covid Support Grant - a grant to support a pilot project exploring whether or not an online retail venture might be an additional profitable income stream.

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

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2022

21 Analysis of net assets between funds

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
Fund balances at 30 June 2022 are represented by:						
Tangible assets	43,398	-	43,398	18,248	-	18,248
Current assets/(liabilities)	242,204	75,273	317,477	205,137	126,698	331,835
Long term liabilities	(34,833)	-	(34,833)	(44,483)	-	(44,483)
	<u>250,769</u>	<u>75,273</u>	<u>326,042</u>	<u>178,902</u>	<u>126,698</u>	<u>305,600</u>

22 Related party transactions

There were no disclosable related party transactions during the year (2021 - Nil).

23 Cash generated from operations

	2022 £	2021 £
Surplus for the year	20,442	24,872
Adjustments for:		
Investment income recognised in statement of financial activities	(57)	(23)
Gain on disposal of tangible fixed assets	(3,915)	-
Depreciation and impairment of tangible fixed assets	8,651	7,499
Movements in working capital:		
(Increase)/decrease in stocks	(3,206)	268
(Increase)/decrease in debtors	(5,966)	39,786
Increase/(decrease) in creditors	2,531	(18,758)
Cash generated from operations	<u>18,480</u>	<u>53,644</u>

24 Analysis of changes in net funds

	At 1 July 2021 £	Cash flows £	At 30 June 2022 £
Cash at bank and in hand	302,502	(16,868)	285,634
Loans falling due within one year	(5,517)	(4,130)	(9,647)
Loans falling due after more than one year	(44,483)	9,650	(34,833)
	<u>252,502</u>	<u>(11,348)</u>	<u>241,154</u>

Alex, The Leukodystrophy Charity

England & Wales - Charity number 1106008

Accounts

Charity registration number 1106008

Company registration number 05142341 (England and Wales)

ALEX, THE LEUKODYSTROPHY CHARITY
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2021

ALEX, THE LEUKODYSTROPHY CHARITY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

L Milne
G Bridge
L Winn
O Bostock
T Watkins
S Jimenez
G Metcalf (Appointed 26 April 2021)
N Sarig (Appointed 26 August 2020)
J Livingston (Appointed 15 May 2022)
I Idafar (Appointed 6 February 2022)

Secretary

Sara Hunt

Charity number

1106008

Company number

05142341

Registered office

45 Peckham High Street
London
SE15 5EB

Independent examiner

Darren Harding ACA FCCA DChA
Richard Place Dobson Services Limited
1-7 Station Road
Crawley
West Sussex
RH10 1HT

ALEX, THE LEUKODYSTROPHY CHARITY

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Statement of cash flows	10
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ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 30 JUNE 2021

The trustees present their annual report and financial statements for the year ended 30 June 2021.

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 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:

- relief of sickness of people with Adrenoleukodystrophy (ALD), Adrenomyeloneuropathy (AMN) and other leukodystrophies and their parents and carers;
- to promote medical research into Adrenoleukodystrophy, Adrenomyeloneuropathy and other leukodystrophies and the publication of useful results of such research for the benefit of the public;
- to advance the education of the public in Adrenoleukodystrophy, Adrenomyeloneuropathy and other leukodystrophies.

The trustees have referred to the guidance in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives in planning its future activities. In particular, they have considered how planned activities will contribute to the aims and objectives they have set.

Achievements and performance

Organisation

Despite the challenges of the period, Alex TLC were able to successfully navigate the organisation through extended periods of lockdown without any losses to staff, and were even able to improve and increase the support services offered.

Government support through local authority grants and the furlough scheme were sufficient to support the charity's retail business and senior staff were able to successfully apply for a variety of Covid-related charitable grants. These two income streams enabled the majority of core costs and salaries to be maintained throughout the period, ensuring our reserve levels were substantially improved ready for the next financial year and the prospect of significantly reduced governmental support.

Our stakeholder network grew significantly, particularly our relationships with pharmaceutical companies engaged in research for the rarer leukodystrophies. This also translated into additional financial support and the inclusion of a wider variety of support and research items in our 2021 Digital Community Weekend. Of equal note, our relationship with the NHS continued to strengthen through our involvement as the patient representative for the NHS England Inherited White Matter Disorders Diagnostic and Management Service and Patient Registry on the Development Committee (Inherited White Matter Disorders (IWMD) is an alternative term for leukodystrophy).

We also nurtured our relationships with peer organisations, and we:

- worked alongside individual condition patient groups on a variety of projects
- joined a new patient group collaboration to influence how newborn screening applications are assessed
- suggested Metabolic Support UK as the additional patient voice representative on the NHSE IWMD Patient Service and Registry Development Committee
- were invited to join the Lysosomal Storage Disorders Collaborative

We were also able to secure specific funding to employ a Beneficiary Support Officer who helped us to increase our digital support and engagement activities to meet the increased needs of our community. This can be evidenced through the substantial increase in support conversations during the period, from answering email queries to conducting home visits by Zoom. During 2019/2020 staff engaged in 298 support conversations, in 2020/21 this increased to 885 – a 197% increase, reflecting not only the burden Covid-19 was placing on our extremely vulnerable beneficiaries, but also the value of increasing staff capacity for engaging with and supporting our community.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

Although the number of new beneficiaries welcomed during the period was broadly similar to the previous year, there were significant increases in the variety of conditions affecting newcomers. Our online visibility improved significantly during this period, thanks to targeted investment, and this is demonstrated by the variety of conditions affecting new beneficiaries coming to us for support. The lack of an increase in new beneficiaries overall may reflect Covid-related changes to NHS priorities and resources for the period, and subsequent reductions in opportunities for accurate diagnosis.

We took the decision to close our beneficiary grant programme temporarily due to uncertainties around income, acknowledging that we could give greater value to a larger number of beneficiaries by taking this step. This financial support programme has since reopened.

CHARITABLE OBJECTIVES

Across the year Alex TLC staff have:

- welcomed 77 new beneficiaries
- delivered 885 support conversations including 106 Zoom home visits, 13 referrals and provision of advocacy at 11 professional meetings
- granted £1,500 to beneficiaries in need (2020: £2,311)
- been invited to present at 2 events – the All Party Parliamentary Group for Newborn Screening and the European Conference of Endocrinology
- attended 11 stakeholder conferences including the ALD Symposium Europe and Rare Disease Drug Repurposing, and attended training events such as Cruse loss and bereavement, and Breaking Down Barriers Diversity and Inclusive Communications.
- been involved in 76 stakeholder discussions and meetings
- attended a new leukodystrophy clinic in Bristol

We were able to further and introduce several projects during the period which are detailed below:

NHS England Inherited White Matter Disorders (IWMD) Diagnostic and Management Service and Patient Registry – Work to further this important project was significantly moved forward during the period and roll out was confirmed for April 2022, delayed due to the impact of Covid-19. Our position as patient voice on the Development Committee has allowed us to work with NHS medical professionals and commissioners to ensure the Registry meets community expectations, and we were asked to conduct a survey to determine what patients wanted to see from a Registry. The results of this survey have been instrumental in several areas and patients, or their parents/carers, will be able to input vital information themselves to demonstrate not only the physical impact of their condition, but also the psychosocial impact for both themselves and those that care for them. This is the first NHS Patient Registry that allows patients to enter their own data and will be ground-breaking in terms of its ability to direct patient care. As mentioned earlier, we were also asked to suggest an additional patient organisation for this project. Following our guidance, Metabolic Support UK were invited to join us as the associate patient representative organisation on the Development Committee.

Newborn screening – we submitted a comprehensive response to a National Screening Committee consultation as part of their review of our original application to add adrenoleukodystrophy (ALD) to the UK newborn screening programme. This response including a targeted campaign website (Screen Our Boys), encouraging our community to submit 34 individual responses, collaborating with Zellweger UK (a condition which would also be identified by ALD testing), and involvement of numerous ALD specialists globally. Although the resultant negative response was disappointing, we were able to confirm a number of viable strategies to further our argument for the next review in 2023.

Support tools for children and young people – this project was advanced significantly and development of a children's book for 8 to 12 year olds to help them understand the implications of a sibling's diagnosis commenced. We sourced an experienced children's health author and illustrator and held two developmental workshops to confirm characters and storyline.

Engagement with under-represented communities – our database audit confirmed that the demographic of our database is below national levels, and we conducted a survey with our community to learn more about how those from under-represented backgrounds perceived our support. Results demonstrated that we are supporting those that come to us very well and no issues were identified, indicating that it is our ability to reach patients from under-represented communities that needs attention. We also changed the imagery on our website to ensure it was welcoming to everyone, a practice which is now actively engaged in all projects. Once the new NHSE IWMD Service begins, we will work closely with providers to learn how we can engage better with patients and their families from different cultural backgrounds, and develop appropriate and sensitive resources to encourage wider uptake of our services.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

Digital Support Services – Our new digital support strategy included a dedicated Covid page, updated weekly, on our website which was visited by 1,596 users. We also provided 13 interactive digital support activities attended by a total of 43 beneficiaries, ranging from networking “Coffee Mornings”, mindfulness sessions, and fun family activities. Although average attendance was low, ranging from 2 to 7 attendees, impact was high with feedback including “The general community feeling is lovely” and “It is very nice to be able to have the time to get together and just talk. For me, this interaction is something I enjoy a lot and look forward to each one.”

NICE – Staff attended two Highly Specialised Appraisals for new leukodystrophy treatments, both of which were unfortunately withdrawn.

Digital Community Weekend 2020 – Our popular Community Weekend event was converted to a digital format and attended by 99 beneficiaries, medical professionals and researchers. Although we couldn't capture the networking experiences of our in-person event, those that attended gained much needed information and support, and, for the first time we were able to include presentations and research updates around a variety of different conditions, which was very well met. The event Impact Report included comments such as “Range of topics was excellent” and “This digital approach has been just as good as 'the real thing'. Well done Alex TLC, and thank you.”. As well as impact for our beneficiaries, the event also provides an opportunity to develop new relationships with a wider range of pharmaceutical organisations, resulting in increases for this income stream.

Genetic counselling – A MSc Student in Genetic and Genomic Counselling at Cardiff University partnered with us on a project to explore family communication following a leukodystrophy diagnosis within the UK as part of his dissertation. As evidenced in our Impact Surveys, anecdotal beneficiary feedback and organisational experience, this is an area of great importance to our community with existing statutory services unable to fully meet needs. Results will feed into a wider project to develop and communicate a support service to assist beneficiaries inform wider family of a new diagnosis and the potential implications.

CHALLENGES

Community fundraising and voluntary income levels continued to be a concern, alongside the challenges of the uncertainty of Covid-19 and our retail business, which was closed for much of the period.

We decided to implement an online charity retail shop utilising a grant from the Social Enterprise Support Fund and supplement income levels. Unfortunately, success of the project was reliant on access to the Kickstart Scheme in tandem with the strict time restraints on the funding, and the Kickstart employees were unable to start until more than halfway through the project. As a result, we were unable to realise the target income necessary to continue the project.

Our Chief Financial Officer position became vacant at the start of the period, and we were unable to fill the role with a suitable candidate, despite best efforts. This lack of capacity meant the Accounts Manager, CEO and Treasurer needed to take on additional duties, and we had to request a filing extension. Despite these difficulties, staff have been able to monitor financial performance to a high level, although the situation has highlighted the necessity of ensuring this role is filled appropriately in the future.

FUTURE

We will look to maintain our increased levels of support staff and activities, optimising the opportunities our partnership with the new IWMD Patient Service and Registry will offer.

New processes have been identified to ensure improved organisational communications in all workstreams, accountability linked to meaningful Key Performance Indicators and regular workload reviews.

We will continue to increase our portfolio of corporate support, focussing on building relationships with pharmaceutical companies and the benefits these bring for both our organisation and the leukodystrophy community.

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

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

Financial review

At the balance sheet date, the charity had unrestricted funds of £182,130 (2020: £126,144) and restricted funds of £123,470 (2020: 154,584)

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 (£210,000). Our reserves are close to this target level, however, these were maintained due to the Government's Covid support package for retail businesses, and the success of grant applications for emergency Covid funding. Our reserve levels are likely to be tested moving forward now this support has ended, and maintenance of these reserve levels are subject to staff capacity to improve pre-Covid income levels.

FUTURE PLANS

Work areas for 2021/2022 include:

- developing engagement strategies and resources with IWMD Service providers
- continuation of an annual Digital Community Weekend event
- commission a research study with Sheffield Hallam University to explore the impact of a cerebral adrenoleukodystrophy (ALD) diagnosis for parents and carers which will strengthen our campaign to add ALD to the UK newborn screening programme
- as further evidence to support our newborn screening campaign, we will commission a scoping study to explore how adult males with ALD perceive newborn screening
- maintain the Beneficiary Engagement Officer role
- launch our first children's support tool, a book to help young children understand a sibling's diagnosis
- review our community and corporate fundraising resources
- review our website

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.

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	
N Long	(Resigned 7 February 2022)
G Bridge	
L Winn	
O Bostock	
S Cork	(Resigned 26 August 2020)
A Warden	(Resigned 15 February 2021)
T Watkins	
S Jimenez	
G Metcalf	(Appointed 26 April 2021)
N Sarig	(Appointed 26 August 2020)
J Livingston	(Appointed 15 May 2022)
I Idafar	(Appointed 6 February 2022)

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, such as parents, 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.

ALEX, THE LEUKODYSTROPHY CHARITY

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

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.

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 trustees report was approved by the Board of Trustees.

.....
L Milne
Trustee

Dated:

.....
S Jimenez
Trustee

Dated:

ALEX, THE LEUKODYSTROPHY CHARITY

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF ALEX, THE LEUKODYSTROPHY CHARITY

I report to the trustees on my examination of the financial statements of Alex, The Leukodystrophy Charity (the charity) for the year ended 30 June 2021.

Responsibilities and basis of report

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

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

Independent examiner's statement

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the ICAEW, which is one of the listed bodies.

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

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

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

Darren Harding ACA FCCA DChA
Richard Place Dobson Services Limited
1-7 Station Road
Crawley
West Sussex
RH10 1HT

Dated:

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 JUNE 2021

		Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 2020 £
	Notes						
<u>Income from:</u>							
Donations and grants	3	24,512	225,206	249,718	68,068	146,273	214,341
Other trading activities	4	482,238	-	482,238	560,082	-	560,082
Investments	5	23	-	23	134	-	134
Other income	6	-	-	-	1,870	-	1,870
Total income		<u>506,773</u>	<u>225,206</u>	<u>731,979</u>	<u>630,154</u>	<u>146,273</u>	<u>776,427</u>
<u>Expenditure on:</u>							
Raising funds	7	439,116	76,048	515,164	470,930	3,214	474,144
Charitable activities	8	16,354	175,589	191,943	84,360	38,996	123,356
Total resources expended		<u>455,470</u>	<u>251,637</u>	<u>707,107</u>	<u>555,290</u>	<u>42,210</u>	<u>597,500</u>
Net incoming/(outgoing) resources before transfers		51,303	(26,431)	24,872	74,864	104,063	178,927
Gross transfers between funds		4,683	(4,683)	-	3,705	(3,705)	-
Net income/(expenditure) for the year/ Net movement in funds		<u>55,986</u>	<u>(31,114)</u>	<u>24,872</u>	<u>78,569</u>	<u>100,358</u>	<u>178,927</u>
Fund balances at 1 July 2020		<u>126,144</u>	<u>154,584</u>	<u>280,728</u>	<u>47,575</u>	<u>54,226</u>	<u>101,801</u>
Fund balances at 30 June 2021		<u><u>182,130</u></u>	<u><u>123,470</u></u>	<u><u>305,600</u></u>	<u><u>126,144</u></u>	<u><u>154,584</u></u>	<u><u>280,728</u></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

BALANCE SHEET

AS AT 30 JUNE 2021

	Notes	2021 £	£	2020 £	£
Fixed assets					
Tangible assets	13		18,248		24,364
Current assets					
Stocks	14	671		939	
Debtors	15	60,045		99,831	
Cash at bank and in hand		302,502		207,818	
		<u>363,218</u>		<u>308,588</u>	
Creditors: amounts falling due within one year	18	<u>(31,383)</u>		<u>(52,224)</u>	
Net current assets			331,835		256,364
Total assets less current liabilities			<u>350,083</u>		<u>280,728</u>
Creditors: amounts falling due after more than one year	19		(44,483)		-
Net assets			<u>305,600</u>		<u>280,728</u>
Income funds					
Restricted funds	21		123,470		154,584
Unrestricted funds - general			182,130		126,144
			<u>305,600</u>		<u>280,728</u>

ALEX, THE LEUKODYSTROPHY CHARITY

BALANCE SHEET (CONTINUED)

AS AT 30 JUNE 2021

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 2021.

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 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

.....
S Jimenez
Trustee

Company registration number 05142341

ALEX, THE LEUKODYSTROPHY CHARITY

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 30 JUNE 2021

	Notes	2021 £	£	2020 £	£
Cash flows from operating activities					
Cash generated from operations	24		53,644		140,481
Investing activities					
Purchase of tangible fixed assets		(1,383)		(3,031)	
Investment income received		23		134	
Net cash used in investing activities			(1,360)		(2,897)
Financing activities					
New bank loans		50,000		-	
Payment of obligations under finance leases		(7,600)		(3,582)	
Net cash generated from/(used in) financing activities			42,400		(3,582)
Net increase in cash and cash equivalents			94,684		134,002
Cash and cash equivalents at beginning of year			207,818		73,816
Cash and cash equivalents at end of year			302,502		207,818

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2021

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 of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

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 £.

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 2021

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 & equipment	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 2021

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.

Net realisable value is the estimated selling price less all estimated costs of completion and costs to be incurred in marketing, selling and distribution.

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.

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

Assets obtained under hire purchase contracts or finance leases are capitalised in the Balance Sheet. Those held under hire purchase contracts are depreciated over their estimated useful lives. Those held under finance leases are depreciated over their estimated useful lives or the lease term, whichever is shorter.

The interest element of these obligations is charged to the Statement of Financial Activities over the relevant period. The capital element of the future payments is treated as a liability.

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

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 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds general 2020 £	Restricted funds 2020 £	Total 2020 £
Donations and gifts	23,512	6,912	30,424	48,468	16,245	64,713
Grants received	1,000	218,294	219,294	19,600	130,028	149,628
	<u>24,512</u>	<u>225,206</u>	<u>249,718</u>	<u>68,068</u>	<u>146,273</u>	<u>214,341</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

3 Donations and grants

(Continued)

Grants receivable for core activities

Bluebird bio	-	-	-	-	32,500	32,500
BBC Children in Need	-	13,166	13,166	-	-	-
Minoryx Therapeutics	-	8,000	8,000	8,000	-	8,000
CAF	-	39,465	39,465	-	-	-
Contact a Family	-	25,000	25,000	-	-	-
The Y Vonne Flux Charitable Trust	-	-	-	1,000	-	1,000
J R Tijou Charitable Trust	-	-	-	2,000	-	2,000
The Rest-Harrow Trust	-	-	-	200	-	200
Marsh Christian Trust	-	-	-	400	-	400
The Sir Cliff Richard Charitable Trust	-	-	-	1,000	-	1,000
Masonic Charity Foundation	-	-	-	1,000	-	1,000
Tokio Marine Kiln Syndicates Limited	-	-	-	4,000	-	4,000
P F Charitable Trust	-	-	-	2,000	-	2,000
The D Olyly Carte	-	-	-	-	3,000	3,000
National Lottery	-	10,000	10,000	-	10,000	10,000
Trustees of F B Baily Thomas Charitable Fund	-	-	-	-	1,000	1,000
Ionis Pharmaceutic	-	-	-	-	3,914	3,914
Globals Make Some Noise	-	-	-	-	50,000	50,000
City of London	-	-	-	-	17,697	17,697
The Corra Foundation Resilience	-	-	-	-	3,374	3,374
The Hobson Charity	-	1,000	1,000	-	1,398	1,398
The Edward Gostling Foundation	-	-	-	-	5,000	5,000
Moondance Foundation	-	-	-	-	2,145	2,145
Garfield Weston Foundation	-	15,000	15,000	-	-	-
Global MSN	-	25,000	25,000	-	-	-
INTERESBA Sarigs Discretion	-	1,000	1,000	-	-	-
Postcode Neighbour	-	20,000	20,000	-	-	-
Social Entrepreneur Support Fund	-	38,713	38,713	-	-	-
The Baily Thomas	-	20,000	20,000	-	-	-
The Grace Trust	1,000	-	1,000	-	-	-
The Sir Jules Thorn Charitable Trust	-	1,000	1,000	-	-	-
The Thomas Sivewright Catto Charitable Trust	-	750	750	-	-	-
Other grants under £500	-	200	200	-	-	-
	<u>1,000</u>	<u>218,294</u>	<u>219,294</u>	<u>19,600</u>	<u>130,028</u>	<u>149,628</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

4 Other trading activities

	Unrestricted funds general 2021 £	Unrestricted funds general 2020 £
Fundraising events	-	5,895
Shop income	270,559	393,274
Shop income - government grants	211,679	160,913
	<u>482,238</u>	<u>560,082</u>

5 Investments

	Unrestricted funds general 2021 £	Unrestricted funds general 2020 £
Interest receivable	23	134
	<u>23</u>	<u>134</u>

6 Other income

	Total 2021 £	Unrestricted funds general 2020 £
Other income	-	1,870
	<u>-</u>	<u>1,870</u>

7 Raising funds

	Unrestricted funds general 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds general 2020 £	Restricted funds 2020 £	Total 2020 £
<u>Fundraising and publicity</u>						
Staging fundraising events	-	-	-	5,188	1,072	6,260
Other fundraising costs	5,919	1,725	7,644	-	-	-
Staff costs	1,203	36,607	37,810	24,847	2,142	26,989
	<u>7,122</u>	<u>38,332</u>	<u>45,454</u>	<u>30,035</u>	<u>3,214</u>	<u>33,249</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

7 Raising funds

(Continued)

Fundraising trading: costs
of goods and other costs

Operating charity shops	141,766	14,874	156,640	146,793	-	146,793
Staff costs	284,197	22,842	307,039	286,225	-	286,225
Depreciation and impairment	6,031	-	6,031	7,877	-	7,877
	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>
Fundraising trading: costs of goods and other costs	431,994	37,716	469,710	440,895	-	440,895
	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>
	<u>439,116</u>	<u>76,048</u>	<u>515,164</u>	<u>470,930</u>	<u>3,214</u>	<u>474,144</u>

8 Charitable activities

	Beneficiary Support	Awareness and Education	Research	Community Weekend	Total 2021	Total 2020
	2021	2021	2021	2021		
	£	£	£	£	£	£
Staff costs	51,367	26,593	1,444	9,661	89,065	64,893
Rates and water	2,087	2,087	-	-	4,174	3,124
Insurance	153	153	-	-	306	1,134
Light and heat	135	136	-	-	271	188
Telephone	384	142	-	-	526	738
Postage and stationery	30	27	-	-	57	102
Advertising	-	519	71	-	590	-
Community Weekend	387	-	-	3,772	4,159	-
Consultancy fees	1,175	3,000	-	10,602	14,777	1,340
Conference costs	38	-	-	-	38	-
Travel costs	-	-	-	-	-	1,807
Subscriptions	548	-	116	-	664	301
Computer costs	3,070	1,704	50	-	4,824	1,818
Legal and professional	151	-	-	-	151	42
Staff training	315	-	-	-	315	401
Repairs & maintenance	222	222	-	-	444	734
Other charitable expenditure	28	-	1	-	29	71
	<u>60,090</u>	<u>34,583</u>	<u>1,682</u>	<u>24,035</u>	<u>120,390</u>	<u>76,693</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

8 Charitable activities	(Continued)					
Grant funding of activities (see note 9)	1,500	-	-	-	1,500	2,312
Share of support costs (see note 10)	42,180	23,432	1,338	-	66,950	40,923
Share of governance costs (see note 10)	1,955	1,086	62	-	3,103	3,428
	<u>105,725</u>	<u>59,101</u>	<u>3,082</u>	<u>24,035</u>	<u>191,943</u>	<u>123,356</u>
Analysis by fund						
Unrestricted funds - general	11,186	4,959	209	-	16,354	84,360
Restricted funds	94,539	54,142	2,873	24,035	175,589	38,996
	<u>105,725</u>	<u>59,101</u>	<u>3,082</u>	<u>24,035</u>	<u>191,943</u>	<u>123,356</u>

For the year ended 30 June 2020

	Beneficiary Support	Awareness and Education	Research	Total 2020
	£	£	£	£
Staff costs	38,630	26,263	-	64,893
Rates and water	1,562	1,562	-	3,124
Insurance	567	567	-	1,134
Light and heat	94	94	-	188
Telephone	568	170	-	738
Postage and stationery	83	19	-	102
Consultancy fees	-	1,340	-	1,340
Travel costs	208	1,599	-	1,807
Subscriptions	270	-	31	301
Computer costs	1,294	524	-	1,818
Legal and professional	42	-	-	42
Staff training	197	204	-	401
Repairs & maintenance	486	248	-	734
Other charitable expenditure	70	-	1	71
	<u>44,071</u>	<u>32,590</u>	<u>32</u>	<u>76,693</u>
Grant funding of activities (see note 9)	2,312	-	-	2,312
Share of support costs (see note 10)	20,781	20,142	-	40,923
Share of governance costs (see note 10)	1,741	1,687	-	3,428
	<u>68,905</u>	<u>54,419</u>	<u>32</u>	<u>123,356</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

8 Charitable activities

(Continued)

Analysis by fund

Unrestricted funds - general	53,021	31,307	32	84,360
Restricted funds	15,884	23,112	-	38,996
	<u>68,905</u>	<u>54,419</u>	<u>32</u>	<u>123,356</u>

9 Grants payable

	Beneficiary Support 2021 £	Beneficiary Support 2020 £
Grants to individuals	1,500	2,312
	<u>1,500</u>	<u>2,312</u>

10 Support costs

	Support costs £	Governance costs £	2021 £	Support costs £	Governance costs £	2020 £
Staff costs	51,294	-	51,294	31,016	-	31,016
Depreciation	1,468	-	1,468	1,310	-	1,310
Insurance	1,006	-	1,006	751	-	751
Telephone	371	-	371	201	-	201
Postage and stationery	63	-	63	38	-	38
IT Costs	6,042	-	6,042	-	-	-
Training and recruitment costs	1,251	-	1,251	520	-	520
Premises expenses	4,820	-	4,820	4,501	-	4,501
Repairs, maintenance and equipment	66	-	66	2,075	-	2,075
Subscriptions	249	-	249	335	-	335
Travel and subsistence	129	-	129	176	-	176
Sundry costs	191	-	191	-	-	-
Legal and professional	-	13	13	-	39	39
Accountancy fees	-	3,000	3,000	-	2,820	2,820
Trustees meeting costs	-	-	-	-	155	155
Other governance costs	-	90	90	-	414	414
	<u>66,950</u>	<u>3,103</u>	<u>70,053</u>	<u>40,923</u>	<u>3,428</u>	<u>44,351</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

10 Support costs (Continued)

Analysed between Charitable activities	66,950	3,103	70,053	40,923	3,428	44,351
	<u>66,950</u>	<u>3,103</u>	<u>70,053</u>	<u>40,923</u>	<u>3,428</u>	<u>44,351</u>

Governance costs include amounts payable to the independent examiner of £3,000 (2020: £3,000) in respect of their independent examination.

11 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

12 Employees

The average monthly number of employees during the year was:

	2021 Number	2020 Number
	24	21
	<u>24</u>	<u>21</u>
Employment costs	2021	2020
	£	£
Wages and salaries	447,727	377,324
Social security costs	28,747	24,309
Other pension costs	8,734	7,490
	<u>485,208</u>	<u>409,123</u>
	<u>485,208</u>	<u>409,123</u>

Key Management Personnel

The trustees consider four (2020: five) staff members to be Key Management Personnel, the total benefit paid to them is £117,581 (2020: £132,555).

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

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

13 Tangible fixed assets

	Plant and machinery	Fixtures, fittings & equipment	Motor vehicles	Total
	£	£	£	£
Cost				
At 1 July 2020	28,932	13,200	27,026	69,158
Additions	1,383	-	-	1,383
Disposals	(2,852)	-	-	(2,852)
At 30 June 2021	27,463	13,200	27,026	67,689
Depreciation and impairment				
At 1 July 2020	22,665	3,960	18,170	44,795
Depreciation charged in the year	4,407	1,320	1,771	7,498
Eliminated in respect of disposals	(2,852)	-	-	(2,852)
At 30 June 2021	24,220	5,280	19,941	49,441
Carrying amount				
At 30 June 2021	3,243	7,920	7,085	18,248
At 30 June 2020	6,268	9,240	8,856	24,364

14 Stocks

	2021	2020
	£	£
Finished goods and goods for resale	671	939

15 Debtors

	2021	2020
	£	£
Amounts falling due within one year:		
Trade debtors	3,219	356
Other debtors	37,163	80,363
Prepayments and accrued income	19,663	19,112
	60,045	99,831

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

16 Loans and overdrafts

	2021 £	2020 £
Bank loans	50,000	-
Payable within one year	5,517	-
Payable after one year	44,483	-

17 Finance lease commitments

Future minimum lease payments due under finance leases:

	2021 £	2020 £
Within one year	-	7,811
Less: future finance charges	-	(211)
	-	7,600

18 Creditors: amounts falling due within one year

	Notes	2021 £	2020 £
Bank loans	16	5,517	-
Obligations under finance leases	17	-	7,600
Trade creditors		10,929	33,377
Other creditors		11,522	7,460
Accruals and deferred income		3,415	3,787
		31,383	52,224

19 Creditors: amounts falling due after more than one year

	Notes	2021 £	2020 £
Bank loans	16	44,483	-

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

20 Retirement benefit schemes

Defined contribution 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.

The charge to profit or loss in respect of defined contribution schemes was £8,734 (2020 - £7,490).

21 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds				
	Balance at 1 July 2020	Incoming resources	Resource expended	Transfer	Balance at 30 June 2021
	£	£	£	£	£
Research	500	-	(500)	-	-
SCHARR Economic Survey	35,712	-	-	-	35,712
Education & Awareness	10,950	10,000	(10,301)	-	10,649
Family Weekend	24,355	(1,342)	(21,893)	-	1,120
Support Services (formerly named Beneficiary Services)	42,603	60,000	(64,367)	(710)	37,526
Technology	3,014	-	-	-	3,014
Digital Support Costs	10,512	-	(10,512)	-	-
Core Costs	6,938	97,587	(103,380)	(673)	472
New Born Screening	20,000	19,048	(5,271)	-	33,777
Social Enterprises	-	38,713	(35,413)	(3,300)	-
Alexander's Disease	-	1,200	-	-	1,200
	<u>154,584</u>	<u>225,206</u>	<u>(251,637)</u>	<u>(4,683)</u>	<u>123,470</u>

	Movement in funds				
	Balance at 1 July 2019	Incoming resources	Resource expended	Transfer	Balance at 30 June 2020
	£	£	£	£	£
Research	-	500	-	-	500
SCHARR Economic Survey	35,712	-	-	-	35,712
Monitoring & Evaluation Officer	5,000	-	-	(5,000)	-
Education & Awareness	13,514	-	(2,564)	-	10,950
Family Weekend	-	24,355	-	-	24,355
Support Services (formerly named Beneficiary Services)	-	53,000	(14,721)	4,324	42,603
Technology	-	6,043	-	(3,029)	3,014
Digital Support Costs	-	17,697	(7,185)	-	10,512
Core Costs	-	24,678	(17,740)	-	6,938
New Born Screening	-	20,000	-	-	20,000
	<u>54,226</u>	<u>146,273</u>	<u>(42,210)</u>	<u>(3,705)</u>	<u>154,584</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

21 Restricted funds

(Continued)

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

SCHARR Economic Survey fund - Funding specifically reserved for a review of the economic survey commissioned for Alex TLC's original National Screening Committee application to add adrenoleukodystrophy to the UK new born screening programme.

Monitoring & Evaluation Officer - Funding to cover the appointment of a Monitoring & Evaluation Officer whose role is to demonstrate the impact of our work to beneficiaries for the public and our funders.

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.

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

Beneficiaries – A fund for work undertaken in the provision of support activities. The transfer out of this fund reflects the purchase of a fixed asset.

Technology - A fund to purchase Gift Aid stock processing technology and optimise charity shop income generation. The tills purchased have been capitalised so a transfer has been put through to represent the fund being spent.

Digital Support Costs - A fund for work undertaken to implement conversion of relevant Alex TLC activities to a digital format as part of our Covid-19 response strategy.

Core Costs - A pool of funds, generated through the emergency Covid-19 grants made available to the charity sector, to cover charitable core costs. The transfer out of this fund reflects the purchase of fixed assets.

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

The Social Enterprise Support fund - a grant to support a pilot project exploring whether or not an online retail venture might be an additional profitable income stream. The transfer out of this fund reflects the Penge Refit costs.

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

22 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2021	2021	2021	2020	2020	2020
	£	£	£	£	£	£
Fund balances at 30 June 2021 are represented by:						
Tangible assets	18,248	-	18,248	24,364	-	24,364
Current assets/(liabilities)	205,137	126,698	331,835	101,780	154,584	256,364
Long term liabilities	(44,483)	-	(44,483)	-	-	-
	<u>178,902</u>	<u>126,698</u>	<u>305,600</u>	<u>126,144</u>	<u>154,584</u>	<u>280,728</u>

ALEX, THE LEUKODYSTROPHY CHARITY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 JUNE 2021

23 Related party transactions

There were no disclosable related party transactions during the year (2020 - Nil).

24 Cash generated from operations	2021 £	2020 £
Surplus for the year	24,872	178,927
Adjustments for:		
Investment income recognised in statement of financial activities	(23)	(134)
Depreciation and impairment of tangible fixed assets	7,499	9,187
Movements in working capital:		
Decrease in stocks	268	396
Decrease/(increase) in debtors	39,786	(52,817)
(Decrease)/increase in creditors	(18,758)	4,922
Cash generated from operations	53,644	140,481

25 Analysis of changes in net funds

	At 1 July 2020 £	Cash flows £	At 30 June 2021 £
Cash at bank and in hand	207,818	94,684	302,502
Loans falling due within one year	-	(5,517)	(5,517)
Loans falling due after more than one year	-	(44,483)	(44,483)
Obligations under finance leases	(7,600)	7,600	-
	<u>200,218</u>	<u>52,284</u>	<u>252,502</u>