

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	(Appointed 15 May 2022)
	I Idafar	(Appointed 6 February 2022)
	E Hadfield-Hudson	(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	
		<hr/>		<hr/>	
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)	
		<hr/>		<hr/>	
Net cash (used in)/generated from financing activities			(5,520)		42,400
			<hr/>		<hr/>
Net (decrease)/increase in cash and cash equivalents			(16,868)		94,684
Cash and cash equivalents at beginning of year			302,502		207,818
			<hr/>		<hr/>
Cash and cash equivalents at end of year			285,634		302,502
			<hr/> <hr/>		<hr/> <hr/>

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
Other trading activities	701,903	699	702,602	482,238

5 Investments

	Unrestricted funds general 2022 £	Unrestricted funds general 2021 £
Interest receivable	57	23

6 Other income

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

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
Fundraising and publicity	39,558	-	39,558	7,122	38,332	45,454

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
	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>
Fundraising trading: costs of goods and other costs	618,617	483	619,100	431,994	37,716	469,710
	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>
	<u>658,175</u>	<u>483</u>	<u>658,658</u>	<u>439,116</u>	<u>76,048</u>	<u>515,164</u>

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
	<u>69,527</u>	<u>29,025</u>	<u>34,180</u>	<u>32,713</u>	<u>165,445</u>	<u>120,390</u>

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	13
Accountancy fees	-	3,300	3,300	-	3,000	3,000
Other governance costs	-	-	-	-	90	90
	<u>42,022</u>	<u>3,326</u>	<u>45,348</u>	<u>66,950</u>	<u>3,103</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>3,103</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 machinery £	Fixtures, fittings & 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				
Depreciation and impairment				
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	44,480	50,000
	<u>44,480</u>	<u>50,000</u>
Payable within one year	9,647	5,517
Payable after one year	34,833	44,483
	<u>44,480</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	34,833	44,483
		<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 1 July 2020	Incoming resources	Resource expended	Transfer	Balance at 1 July 2021	Incoming resources	Resource expended	Transfer	Balance at 30 June 2022
	£	£	£	£	£	£	£	£	£
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>