

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 N Sarig J Livingston I Idafar	(Appointed 26 April 2021) (Appointed 26 August 2020) (Appointed 15 May 2022) (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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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.

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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		506,773	225,206	731,979	630,154	146,273	776,427
<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		455,470	251,637	707,107	555,290	42,210	597,500
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		55,986	(31,114)	24,872	78,569	100,358	178,927
Fund balances at 1 July 2020		126,144	154,584	280,728	47,575	54,226	101,801
Fund balances at 30 June 2021		182,130	123,470	305,600	126,144	154,584	280,728

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><u>305,600</u></u>		<u><u>280,728</u></u>
Income funds					
Restricted funds	21		123,470		154,584
Unrestricted funds - general			182,130		126,144
			<u><u>305,600</u></u>		<u><u>280,728</u></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	
		<hr/>		<hr/>	
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)	
		<hr/>		<hr/>	
Net cash generated from/(used in) financing activities			42,400		(3,582)
			<hr/>		<hr/>
Net increase in cash and cash equivalents			94,684		134,002
Cash and cash equivalents at beginning of year			207,818		73,816
			<hr/>		<hr/>
Cash and cash equivalents at end of year			302,502		207,818
			<hr/> <hr/>		<hr/> <hr/>

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 Childrean 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 Charitabl	-	-	-	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 Oyly Carte	-	-	-	-	3,000	3,000
National Lottery	-	10,000	10,000	-	10,000	10,000
Trustees of F B Bailly 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 Bailly 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>
Other trading activities	<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>
Fundraising and publicity	<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> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </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> </u>	<u> </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> </u>	<u> </u>
	485,208	409,123
	<u> </u>	<u> </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 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 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	-
	200,218	52,284	252,502