

COMPANY REGISTRATION NUMBER: 3557191
CHARITY REGISTRATION NUMBER: 1071196

Alström Syndrome UK
Company Limited by Guarantee
Unaudited Financial Statements
31 March 2023

WESTCOTTS

Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alström Syndrome UK

Company Limited by Guarantee

Financial Statements

Year ended 31 March 2023

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Alström Syndrome UK

Company Limited by Guarantee

Trustees' Annual Report (Incorporating the Director's Report)

Year ended 31 March 2023

The trustees, who are also the directors for the purposes of company law, present their report and the unaudited financial statements of the charity for the year ended 31 March 2023.

Reference and administrative details

Registered charity name Alström Syndrome UK

Charity registration number 1071196

Company registration number 3557191

Principal office and registered office 4 St Kitts Close
Torquay
TQ2 7GD
Devon

The trustees	Prof. Timothy Barrett	
	Sharon Bates	
	Jane Biglin	(Appointed 18 July 2022)
	Melissa Crowland	
	Haris Hamid	
	Kez Hayat	(Retired 22 October 2022)
	Dr Richard Paisey	(Retired 22 October 2023)
	Trevor Parkin	(Appointed 21 June 2023)
	Carol Prescott	
	Katie Staddon	(Appointed 22 March 2023)
	Retired 25 October 23)	
	Mathilde Yates	(Appointed 18 July 2022)

Independent examiner Catherine Williams FCA DChA
Westcotts (SW) LLP
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alström Syndrome UK

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2023

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

The organisation is a charitable company, limited by guarantee, incorporated on 1st May 1998 and registered as a charity in the UK on 25th August 1998. The company was established under a memorandum of association which established the objectives and powers of the charitable company and is governed under its articles of association.

Recruitment and Appointment of Trustees

The Directors of the company are also charity Trustees for the purpose of charity law.

New Trustees are appointed by the existing Trustees and serve for three years after which they may put themselves forward for re-appointment. Trustees can serve a maximum of three terms of three years, a total of nine years at which point they must resign from the board. They can serve on an Alström Syndrome UK (ASUK) patient advisory or project group after this. If a vacancy becomes available, they may apply to re-join the Board after a period of 12 months. The Board actively recruit those who are directly affected by Alström Syndrome (AS) and family members, ensuring that the charity remains patient led and those with lived experience remain at the heart of the work of the charity.

Induction and Training of Trustees

New Trustees are given a copy of the memorandum and articles of association and are given copies of the Charity Commission guidance "The Essential Trustee: What you need to know, what you need to do" as well as links to the Charity Commission and Government website outlining the responsibilities of the Trustee role.

New Trustees have a six-month induction period during which they can be assigned a Trustee mentor who can provide advice and guidance. New Trustees receive an induction pack containing key information to gain a further understanding of ASUK and its' strategic priorities, and an opportunity to observe at a board meeting. They are invited to meet with the Board of Trustees, the Chief Executive and the staff team as well as patients and their families.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2023

OBJECTIVES AND ACTIVITIES

Public benefit

The Trustees have complied with section 4 of the Charities Act 2006 in regard to the public benefit requirement.

Objectives and activities

Purposes and aims

ASUK's objectives, as set out in the company's memorandum of association, are;

1. The relief of sickness of persons with Alström Syndrome, in particular, but not exclusively by the provision of support, advice and information for such persons their families, carers and those working with affected individuals.
2. The promotion of research into Alström Syndrome and related syndromes in the UK and abroad and the public dissemination of the useful results thereof.

ACHIEVEMENTS AND PERFORMANCE

ASUK continues to provide person centred and flexible support to individuals and families affected by AS. On the 31st March 2023, we know of 88 people diagnosed with AS in the UK; 52 were born male, 36 born female and 53% are from an ethnic minority community. We always try to ensure that the support we provide is as accessible and equitable as possible and do what we can to remove any barriers and remain inclusive in our approach.

The highly specialised multi-disciplinary clinics have returned to in person clinics as requested by patients, parents and carers. A small number of people have chosen to continue with virtual consultations due to their concerns and fear of Covid-19. ASUK continue to support at every AS clinic and offer ongoing support by telephone, email and home visits. We take advantage of technology and the developments made throughout the Covid-19 pandemic and meet with people online if preferred.

AS Highly Specialised Clinics during 2022-2023

Paediatric Clinics – Birmingham Women's & Children's Hospital

- 1 Virtual Clinic
- 1 Hybrid Clinic
- 3 In-Person Clinics (BWCH)
- 1 Outreach Clinic (St James's Hospital, Leeds)

Adult Clinics – Queen Elizabeth Hospital, Birmingham

- 3 Hybrid Clinics
- 3 In-Person Clinics
- Additional Outpatient Appointments

There was no transfer clinic this year. Three young people are preparing to transfer in May 2023. This has been a challenging year for ASUK as 6 people have sadly passed away. This is the highest number of deaths we have had in one year. We continue to support bereaved families and the AS community as best we can. Losing a member of the AS community is devastating and impacts on everyone.

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Year ended 31 March 2023

We have also seen a record number of new referrals during 2022-23. 9 people have received a diagnosis and 8 of those are under the age of 10 years. It is positive to see that there is some evidence to suggest that the time it takes to receive a diagnosis is reducing.

We have 2 AS Care Coordinators and a Transition Coordinator as part of the Family Support Service. The service is overseen by the Chief Executive, supported by the Office Manager. We conduct a review on a quarterly basis where we discuss each person/family. We have a good understanding of the individual needs of our members and provide personalised support where possible. We have a very diverse patient population with a range of complex needs. We provide emotional and practical support and there has been a significant increase in the demand on our services due to the Covid-19 pandemic, followed by a cost-of-living crisis. We provide advice on benefits, provide access to grants, contribute to education and social care assessments, and liaise between individuals, parents, carers, local and specialist service providers.

Through our grants programmes we have been able to provide a range of different exercise equipment and fund outdoor activities to support people to remain as active as possible. We have provided funding through our Adult Empowerment grants for those over 18 years to visit new places of interest and to challenge themselves to try new activities and develop independence. It has been lovely to see people getting out and about again in their local community and having short breaks away. We have also been working with local authorities and different charities to ensure people have access to cost-of-living grants and emergency essential food and equipment.

Following consultation, the Culture Sparkle Sisters have chosen to change their name to The ASUK Culture Family Forum and have welcomed new members on board. The group meet regularly online and invite guests to discuss specific topics. They provide advice and feedback to ASUK on our projects and the accessibility of products and services.

We have increased our reach throughout the year. We have been raising awareness of AS and sharing information about the condition and the support we offer as an organisation. Information is shared through our ASUK and Breaking Down Barriers (BDB) websites, newsletters, email circulations, over the telephone and via social media platforms. We also take part in events throughout the rare disease community and sit on various committees and steering groups. During the year we had 95465 visits to the ASUK website with 59021 unique visitors. We reached 10577 people on the ASUK Facebook page and had 27979 impressions on Twitter.

We have extended our reach and international collaborations through the development of AS Global. With the support of our global partners, we have run 9 webinars throughout the year for patients, parents, carers and professionals. Webinars are recorded and added to the ASUK website with top tips and links to further information and resources, creating bite sized learning modules for families anywhere in the world. We held a virtual conference in December 2022 which included over 100 attendees from 24 countries.

We have developed a new website for BDB and the network has grown to over 60 organisations working together to provide support to people affected by rare and genetic conditions. We work together to learn, develop, and share good practice. Promoting equity, diversity and inclusion is at the centre of what we do. Our Experts by Experience Advisory Group help us to understand the lived experiences of people from diverse and marginalised communities who are affected by rare and genetic conditions. We create safe and supportive spaces for learning and collaboration, deliver training and development and run a community outreach project in West Yorkshire. We unite and strive for equitable access to services and support for all.

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Year ended 31 March 2023

We continue to work in partnership with the Department of Health & Social Care to run a focus group to understand the health inequalities experienced by people from diverse and marginalised communities who are also affected by a rare condition. Findings from these focus groups are fed into England's Rare Diseases Action Plan that is published on Rare Disease Day.

We are incredibly grateful to the Sylvia Adams Charitable Trust for their generosity and continuous support. As a time limited organisation, they have now closed their doors but have kindly provided legacy funding to enable BDB to continue in the short term to give us time to bring new funders on board.

Our grant application to Contact and The Pears Foundation was successful and has enabled us to start updating T-KASH (Transition – Knowledge And Skills in Healthcare). T-KASH resources were originally created in 2015 by young people from the ASUK, Hear My Voice Youth Forum. These free resources are designed to support young people, families, and healthcare professionals, to help everyone understand the transition journey and the things that are important to young people as they grow up. At the end of 2022, we began the process of updating the T-KASH resources to ensure they are inclusive and represent the diverse needs of young people within the rare disease community. With the support of the BDB Experts by Experience Advisory Group and our youth and young adult advisors, we are updating T-KASH and creating brand new resources, including an animation that we hope will be used throughout the BDB network and beyond. These resources will be available from September 2023.

We have continued to work more broadly within the rare disease community, in the UK and beyond. We recognise that as a small organisation, we are much stronger when working together with other organisations. Embedding the diverse views of people with lived experience is essential in all that we do.

Key Achievements and Performance

During the year we:

- Maintained our record of 100% attendance at clinics
- Continued to work with the hospital teams to review and improve the clinics based on patient needs, evaluation, and feedback
- Provided support and information to newly diagnosed individuals, families and the professionals working with them
- Facilitated online groups for young people and adults to meet and offer peer to peer support
- Provided **21** small grants to empower people to exercise and develop independence, towards the cost of funerals and to support with the cost-of-living
- Provided **2** Adult Empowerment grants for adults to visit new places of interest or to try a new activity
- Provided virtual and face to face activities and events
- Encouraged healthy lifestyles through information, support and global webinars
- Increased the BDB Network to **65** organisations
- The BDB 'Would you exclude me?' animation has received **135** views during the year
- Delivered **4** BDB webinars and training events

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Year ended 31 March 2023

- Developed new global connections and established partnerships
- Encouraged worldwide completion of the Patient Registry
- Hosted a Global Alström Conference with **117** registered attendees from **24** different countries bringing together the Alström community from around the world
- Improved communications & increased our reach - the ASUK website had **95,500** views
- Increased awareness and extended our reach using multimedia communication channels
- Delivered **8** presentations about AS, ASUK and BDB – including presentations at Cilia 2022 in Cologne and in the DHSC Away Day in London
- Provided the secretariat for Alström Europe (ASEU)
- Achieved a positive outcome from grant applications and demonstrated effective cost control
- Acted prudently and resourcefully to ensure we control expenditure and make the most of income and donations
- Supported the ASUK team

Research

The AS Medical and Scientific Advisory Group met in December 2022, chaired by Professor Rick Steeds, Cardiologist for the AS Adult Service. It was encouraging to hear about developments in clinical and scientific research. There are new medications available to treat obesity, diabetes and cardiac conditions and these are being used and monitored closely by the adult team. We now have an AS mouse model in Edinburgh with research being led by Professor Rob Semple and Dr Eleanor McKay. We are grateful to all our medical and scientific colleagues for the work they do to try to improve the health outcomes for people diagnosed with AS now and in the future.

Future aims

In May 2023, ASUK will celebrate its 25th anniversary. We will take time to reflect on how far the charity has developed over the years, take stock of where we are now and look ahead to the future. We look forward to celebrating with the AS community and to continuing to develop and improve the support we provide.

The Board of ASUK is committed to providing even more grants, activities and events for children, young people, adults, families and carers. We would also like to provide opportunities to bring people together who would like to meet up in person where possible.

We are excited to explore new research opportunities in the hope that we can learn more about the condition and deliver research that will eventually lead to new treatments and improve the management of AS and the experiences of those affected by the condition.

We will continue to work collaboratively with the UK and international community through BDB, ASEU and AS Global.

We will continue to strengthen our governance to ensure we have an effective and proactive Board.

We will invest and care for our staff team and each other to develop skills, abilities and resilience.

We will ensure that people living with AS always remain at the heart of everything we do.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2023

Chairs Review

I am pleased to present our annual report and accounts for 2022-23 for my first year as the new chair of the Board of Trustees.

I would like to start by thanking Trevor Parkin, who stood down as chair of the Board of Trustees in the last 12 months, for all of his contribution to the Board and the charity.

We have been delighted that he has continued to be involved with the charity in another voluntary role, so we have not lost his knowledge and lived experience.

The Board has also seen Kez Hayat retire this year and we thank him for all of his input to the Board and the charity. Again, he has continued to offer support to the charity in another voluntary role. We have also recruited 3 new Trustees Jane Biglin, Mokey Yates and Katie Staddon who compliment the Board which now has 9 members who provide a diverse range of experience and knowledge to the charity.

We continue to see the impact of recovery from the covid pandemic and in addition the cost-of-living pressures however it has been a successful year for ASUK as this report demonstrates. Hospital adult and children's clinics are now fully back on course and we support individuals and families in attending these. We have been able to provide a number of ASUK grants to individuals and families and also help them obtain other appropriate funding to support them during some difficult financial times.

Our amazing team of staff continue to provide an outstanding service and work together in a way that puts the Alstrom community at the centre of everything they do.

We have been working hard to continue to increase awareness of AS and promoting the work ASUK does, both in the UK and globally. We are looking at how we can get more involved with research opportunities, and I am confident we will have more news on this next year.

The charity goes from strength to strength led by our Chief Executive who has settled well into her new role over the last 12 months and our strategy to share our knowledge and further develop relationships globally is coming to fruition due to the work of our Executive Director. We are looking forward to the 25th anniversary of the charity next year where we plan more ways to celebrate the work of the charity and community it supports.

Tackling health inequalities, highlighted even more by the pandemic, remains an important part of our work. The BDB project continues to develop, reaching more and more organisations supporting people with rare and genetic conditions. With funding and support from the Sylvia Adams Charitable Trust, we have been able to continue the work of the BDB team. Our thanks go to the BDB Advisory Group and to the Sylvia Adams Charitable Trust who have continued to advise, support and fund this important project since it started in 2016. It is great to see the difference this project is making and the opportunities it creates for us to collaborate with others and to influence research and UK policy.

I would like to take this opportunity to thank the Board members for their tireless work and commitment to our community and the team at ASUK who are a pleasure to work with.

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Year ended 31 March 2023

Finally, may I say a heartfelt thank you to our community and supporters for your contribution; raising funds and awareness of this ultra-rare condition that is Alström Syndrome.

Kindest Regards

Sharon Bates
Chair of the Board of Alström Syndrome UK

Financial Review

The General Fund had a surplus of £9,842 stands at £197,585 (2022 £187,743).

The Trustees hold the following designated funds:

- Fixed Assets £4,088
- Research Fund £20,000
- Financial Assistance Grant Fund £14,587
- Adult Empowerment Grant Fund £17,618

The Trustees made grants of £4,990 from the Financial Assistance Grant Fund and £1,000 from the Adult Empowerment Grant Fund. The trustees hold a total designated funds of £56,293 (2022 £64,227)

The restricted funds stand at £24,000 (2022 £19,796).

Reserves Policy and Going Concern

The Trustees review the level of reserves on a regular basis to ensure that the appropriate levels are maintained considering the main risks to the organisation and future developments. The following designated reserves are held at the year-end:

Financial Assistance Grant Fund £14,587 - Amount set aside to provide financial support to AS patients, and their families based upon an assessment of need.

Adult Empowerment Grant Fund £17,618 - Amount set aside to enable and empower adults with AS, to be used for a variety of activities that improve their ability to self-advocate, to meet up with other adults and try something new. Funds may also be used to improve communication and confidence for adults with AS.

Research Fund £20,000 – Amount set aside to fund research into AS.

Fixed Assets Fund £4,088 which cannot be used to fund expenditure without being sold.

The remaining reserves of £197,585 are held in the General Fund.

The Trustees have reviewed the circumstances of the charity and consider that adequate resources continue to be available to fund its activities for the foreseeable future. The Trustees are of the view that the charity is a going concern.

Alström Syndrome UK

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2023

Management of Risk

The Trustees have identified that the main risks to the charity are:

1. The loss of the NHS England clinic contract
2. The loss of key personnel
3. Failing to secure sufficient funds

The Trustees monitor the risks through quarterly reports and regular updates with staff.

Small company provisions

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

The trustees' annual report was approved on 22nd November 2023 and signed on behalf of the board of trustees by:



Sharon Bates
Trustee

Alström Syndrome UK

Company Limited by Guarantee

Independent Examiner's Report to the Trustees of Alström Syndrome UK

Year ended 31 March 2023

I report to the trustees on my examination of the financial statements of Alström Syndrome UK ('the charity') for the year ended 31 March 2023.

Responsibilities and basis of report

As the trustees of the company (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 accounts of the company 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 accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the 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 Institute of Chartered Accountants in England and Wales (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:

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 accounts to be reached.



Catherine Williams FCA DChA
Westcotts (SW) LLP
Independent Examiner
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

1st December 2023

Alström Syndrome UK

Company Limited by Guarantee

Statement of Financial Activities (including income and expenditure account)

Year ended 31 March 2023

		Unrestricted funds £	2023 Restricted funds £	Total funds £	2022 Total funds £
	Note				
Income and endowments					
Donations and legacies	5	3,712	—	3,712	1,449
Charitable activities	6	202,475	163,815	366,290	298,164
Investment income	7	766	—	766	411
Total income		<u>206,953</u>	<u>163,815</u>	<u>370,768</u>	<u>300,024</u>
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and legacies	8	216	—	216	216
Expenditure on charitable activities	9,10	204,829	159,791	364,620	302,977
Total expenditure		<u>205,045</u>	<u>159,791</u>	<u>364,836</u>	<u>303,193</u>
Net income/(expenditure) and net movement in funds		<u>1,908</u>	<u>4,024</u>	<u>5,932</u>	<u>(3,169)</u>
Reconciliation of funds					
Total funds brought forward		251,970	19,976	271,946	275,115
Total funds carried forward		<u>253,878</u>	<u>24,000</u>	<u>277,878</u>	<u>271,946</u>

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

The notes on pages 13 to 23 form part of these financial statements.

Alström Syndrome UK

Company Limited by Guarantee

Statement of Financial Position

31 March 2023

	Note	2023 £	2022 £
Fixed assets			
Tangible fixed assets	16	4,088	6,032
Current assets			
Debtors	17	38,613	169,356
Investments	18	85,000	85,000
Cash at bank and in hand		171,612	143,896
		<u>295,225</u>	<u>398,252</u>
Creditors: amounts falling due within one year	19	<u>21,435</u>	<u>132,338</u>
Net current assets		<u>273,790</u>	<u>265,914</u>
Total assets less current liabilities		<u>277,878</u>	<u>271,946</u>
Net assets		<u>277,878</u>	<u>271,946</u>
Funds of the charity			
Restricted funds		24,000	19,976
Unrestricted funds		<u>253,878</u>	<u>251,970</u>
Total charity funds	21	<u>277,878</u>	<u>271,946</u>

For the year ending 31 March 2023 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

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

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

These financial statements were approved by the board of trustees and authorised for issue on 22nd November 2023 and are signed on behalf of the board by:



Sharon Bates
Trustee

The notes on pages 13 to 23 form part of these financial statements.

Alström Syndrome UK

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Notes to the Financial Statements

Year ended 31 March 2023

1. General information

The charity is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is 4 St Kitts Close, Torquay, TQ2 7GD, Devon.

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the 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) (Charities SORP (FRS 102)) and the Companies Act 2006.

3. Accounting policies

Basis of preparation

The financial statements have been prepared on the historical cost basis. The financial statements are prepared in sterling which is the functional currency of the charity.

Going concern

There are no material uncertainties about the charity's ability to continue.

Disclosure exemptions

Under Charities SORP (FRS 102) the Charity is classed as a small charity and has therefore taken the exemption from the requirement to prepare a cashflow statement.

Judgements and key sources of estimation uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

3. Accounting policies *(continued)*

Incoming resources

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

3. Accounting policies *(continued)*

Tangible assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses. The Trustees consider capitalising fixed assets costing £250 or more.

Depreciation

Depreciation is calculated so as to write off the cost or valuation of an asset, less its residual value, over the useful economic life of that asset as follows:

Computer Equipment - 25% straight line

Financial instruments

A financial asset or a financial liability is recognised only when the entity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs, unless the arrangement constitutes a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised as an expense in the period in which it arises.

4. Limited by guarantee

The Company is limited by guarantee, having no share capital. It is a registered charity. Under the provisions of Section 30 of the Companies Act 2006, the company is entitled to omit the word "Limited" from its name. In the event of the company being wound up, the liability of each member is limited to £10.

Alström Syndrome UK

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

5. Donations and legacies

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Donations				
General Donations	3,712	3,712	1,449	1,449

6. Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Unrestricted Grants	10,000	–	10,000
NHS Commissioning	171,061	–	171,061
Transition Activities	–	22,900	22,900
Breaking Down Barriers	–	132,415	132,415
Sundry income	21,414	–	21,414
Pears	–	8,500	8,500
	<u>202,475</u>	<u>163,815</u>	<u>366,290</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Unrestricted Grants	4,000	–	4,000
NHS Commissioning	165,602	–	165,602
Transition Activities	–	24,725	24,725
Breaking Down Barriers	–	75,000	75,000
Sundry income	19,137	–	19,137
Pears	–	9,700	9,700
	<u>188,739</u>	<u>109,425</u>	<u>298,164</u>

7. Investment income

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Investment income	766	766	411	411

8. Costs of raising donations and legacies

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Administration costs	216	216	216	216

Alström Syndrome UK

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

9. Expenditure on charitable activities by fund type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
NHS Commissioning	138,072	–	138,072
Fixed assets	1,944	–	1,944
Transition Activities	–	26,114	26,114
Breaking Down Barriers	–	122,683	122,683
Financial Assistance Grant Fund	4,990	–	4,990
Family Support	–	3,054	3,054
Adult Empowerment Grant fund	1,000	–	1,000
Pears	–	7,940	7,940
Support costs	58,823	–	58,823
	<u>204,829</u>	<u>159,791</u>	<u>364,620</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
NHS Commissioning	118,708	–	118,708
Fixed assets	2,678	–	2,678
Transition Activities	–	33,047	33,047
Breaking Down Barriers	–	106,631	106,631
Financial Assistance Grant Fund	869	–	869
Family Support	–	–	–
Adult Empowerment Grant fund	–	–	–
Pears	–	9,700	9,700
Support costs	31,344	–	31,344
	<u>153,599</u>	<u>149,378</u>	<u>302,977</u>

10. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	Total funds 2023 £	Total fund 2022 £
NHS Commissioning	138,072	–	138,072	118,708
Fixed assets	1,944	–	1,944	2,678
Transition Activities	26,114	–	26,114	33,047
Breaking Down Barriers	122,683	–	122,683	106,631
Financial Assistance Grant Fund	4,990	–	4,990	869
Support costs	–	58,823	58,823	31,344
Family Support	3,054	–	3,054	–
Adult Empowerment Grant fund	1,000	–	1,000	–
Pears	7,940	–	7,940	9,700
	<u>305,797</u>	<u>58,823</u>	<u>364,620</u>	<u>302,977</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

11. Analysis of support costs

	Support costs	Total 2023	Total 2022
	£	£	£
Staff costs	43,275	43,275	22,376
Membership fees	334	334	325
Sundry Expenses	3,769	3,769	183
Telephone and Fax	984	984	991
Insurance	909	909	734
Accountancy fees	1,164	1,164	1,110
Contractors fees	5,990	5,990	5,600
Hotels, traveling and subsistence costs	1,774	1,774	–
Printing, postage, stationery and advertising	624	624	25
	<u>58,823</u>	<u>58,823</u>	<u>31,344</u>

12. Net income/(expenditure)

Net income/(expenditure) is stated after charging/(crediting):

	2023	2022
	£	£
Depreciation of tangible fixed assets	1,944	2,105
Loss on disposal of tangible fixed assets	–	573
	<u>–</u>	<u>–</u>

13. Independent examination fees

	2023	2022
	£	£
Fees payable to the independent examiner for:		
Independent examination of the financial statements	2,328	2,220
Other services	2,000	–
	<u>4,328</u>	<u>2,220</u>

14. Staff costs

The total staff costs and employee benefits for the reporting period are analysed as follows:

	2023	2022
	£	£
Wages and salaries	206,107	182,501
Social security costs	14,574	12,438
Employer contributions to pension plans	9,432	8,074
Other employee benefits	1,857	1,135
	<u>231,970</u>	<u>204,148</u>

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

14. Staff costs *(continued)*

The average head count of employees during the year was 8 (2022: 7). The average number of full-time equivalent employees during the year is analysed as follows:

	2023 No.	2022 No.
Staff	<u>6</u>	<u>5</u>

No employee received employee benefits of more than £60,000 during the year (2022: Nil).

15. Trustee remuneration and expenses

No Trustee received remuneration during the year or the previous year. No Trustee or other person related to the Charity had any personal interest in any contract entered into by the Charity during the year.

During the year, Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustee meetings these claims totalled £1,037 (2022 £Nil)

16. Tangible fixed assets

	Computer Equipment £
Cost	
At 1 April 2022 and 31 March 2023	<u>13,012</u>
Depreciation	
At 1 April 2022	6,980
Charge for the year	<u>1,944</u>
At 31 March 2023	<u>8,924</u>
Carrying amount	
At 31 March 2023	<u>4,088</u>
At 31 March 2022	<u>6,032</u>

17. Debtors

	2023 £	2022 £
Trade debtors	21,150	—
Prepayments and accrued income	<u>17,463</u>	<u>169,356</u>
	<u>38,613</u>	<u>169,356</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

18. Investments

	2023 £	2022 £
Deposits	<u>85,000</u>	<u>85,000</u>

19. Creditors: amounts falling due within one year

	2023 £	2022 £
Trade creditors	541	—
Accruals and deferred income	7,653	6,030
Social security and other taxes	<u>13,241</u>	<u>126,308</u>
	<u>21,435</u>	<u>132,338</u>

20. Pensions and other post retirement benefits

Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £9,432 (2022: £8,074).

Alström Syndrome UK

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

21. Analysis of charitable funds

Unrestricted funds

	At 1 April 2022 £	Income £	Expenditure £	Transfers £	At 31 March 2023 £
General Funds	187,743	206,953	(197,111)	–	197,585
Financial Assistance Grant Fund	19,577	–	(4,990)	–	14,587
Adult Empowerment Grant Fund	18,618	–	(1,000)	–	17,618
Fixed Assets	6,032	–	(1,944)	–	4,088
Research Fund	20,000	–	–	–	20,000
	<u>251,970</u>	<u>206,953</u>	<u>(205,045)</u>	<u>–</u>	<u>253,878</u>

	At 1 April 2021 £	Income £	Expenditure £	Transfers £	At 31 March 2022 £
General Funds	188,210	190,599	(150,268)	(40,798)	187,743
Financial Assistance Grant Fund	10,446	–	(869)	10,000	19,577
Adult Empowerment Grant Fund	8,618	–	–	10,000	18,618
Fixed Assets	5,957	–	(2,678)	2,753	6,032
Research Fund	–	–	–	20,000	20,000
	<u>213,231</u>	<u>190,599</u>	<u>(153,815)</u>	<u>1,955</u>	<u>251,970</u>

General Fund

General funds are donations and other incoming resources receivable or generated for the objects of the charity without further specific purpose and which the charity may use for its purpose at its discretion.

Financial Assistance Grant Fund

Amount set aside to provide financial support to Alström patients and their families based upon an assessment of need.

Adult Empowerment Grant Fund

Amount set aside to enable and empower adults with Alström to be used for a variety of activities that improve their ability to self-advocate and to meet up with other adults. Funds may also be used to improve communication and confidence for adults with Alström.

Fixed Assets

Fixed Assets which cannot be used to fund expenditure without being sold.

Research Fund

Wording for Research Fund – Amount set aside to fund research into Alström Syndrome.

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

21. Analysis of charitable funds *(continued)*

Restricted funds

	At 1 April 2022 £	Income £	Expenditure £	Transfers £	At 31 March 2023 £
<u>Transition Activities</u>					
Children in Need	5,969	22,900	(26,114)	–	2,755
<u>Sylvia Adams Trust</u>					
Breaking down Barriers	10,953	132,415	(122,683)	–	20,685
<u>Family Support</u>					
Smaller restricted Funds	3,054	–	(3,054)	–	–
Pears	–	8,500	(7,940)	–	560
	<u>19,976</u>	<u>163,815</u>	<u>(159,791)</u>	<u>–</u>	<u>24,000</u>

	At 1 April 2021 £	Income £	Expenditure £	Transfers £	At 31 March 2022 £
<u>Transition Activities</u>					
Children in Need	14,291	24,725	(33,047)	–	5,969
<u>Sylvia Adams Trust</u>					
Breaking down Barriers	44,539	75,000	(106,631)	(1,955)	10,953
<u>Family Support</u>					
Smaller restricted Funds	3,054	–	–	–	3,054
Pears	–	9,700	(9,700)	–	–
	<u>61,884</u>	<u>109,425</u>	<u>(149,378)</u>	<u>(1,955)</u>	<u>19,976</u>

Children In Need

Funding towards a Transitions Coordinator, support groups for young people and activities

Breaking down Barriers

Funding to facilitate patient organisations and support groups to join together to share examples of good practice and develop new guidelines to highlight effective ways to support families.

Pears

Enabling our team to meet the unprecedented, increasing demand on our support services

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

22. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Tangible fixed assets	4,088	–	4,088
Current assets	265,454	29,771	295,225
Creditors less than 1 year	(15,664)	(5,771)	(21,435)
Net assets	<u>253,878</u>	<u>24,000</u>	<u>277,878</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Tangible fixed assets	6,032	–	6,032
Current assets	370,871	27,381	398,252
Creditors less than 1 year	(124,933)	(7,405)	(132,338)
Net assets	<u>251,970</u>	<u>19,976</u>	<u>271,946</u>

23. Related parties

During the year there were no related party transactions (2022: None)