

Company registration number: 3557191

Charity registration number: 1071196

Alström Syndrome UK

(A company limited by guarantee)

Annual Report and Financial Statements

for the Year Ended 31 March 2024



Alström Syndrome UK

Reference and Administrative Details

Trustees: Prof Timothy Barrett
Sharon Bates
Jane Biglin
Melissa Crowland (resigned 31 March 2024)
Haris Hamid
Tarekegn Hiwot
Alexandra Line (appointed 1 April 2024)
Richard Paisey (resigned 22 November 2023)
Trevor Parkin (appointed 21 June 2023)
Carol Prescott
Katie Stadden (resigned 25 October 2023)
Mathilde Yates

Charity Registration Number 1071196

Company Registration Number 3557191

Registered Office The charity is incorporated in England & Wales.
4 St Kitts Close
Torquay
Devon
TQ2 7GD

Independent Examiner Westcotts (SW) LLP
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alström Syndrome UK

Trustees' Report

The trustees, who are directors for the purposes of company law, present the annual report together with the financial statements of the charitable company for the year ended 31 March 2024.

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

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.

ASUK Board of Trustees

- Richard Paisey, appointed on 7th February 2015, retired on 22nd November 2023
- Sharon Bates, appointed on 2nd November 2019
- Tim Barrett, appointed on 2nd November 2019
- Melissa Crowland, appointed on 2nd November 2019, retired on 31st March 2024
- Haris Hamid, appointed on 9th March 2022
- Carol Prescott, appointed on 9th March 2022
- Jane Biglin, appointed on 18th July 2022
- Mathilde Yates, appointed on 18th July 2022
- Katie Staddon, appointed on 22nd March 2023, retired on 25th October 2023
- Trevor Parkin, appointed on 21st June 2023
- Tarekegn Hiwot, appointed on 23rd November 2023

Alström Syndrome UK

Trustees' Report

OBJECTIVES AND ACTIVITIES

Public benefit

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

Alström Syndrome UK (ASUK) has a skilled and experienced team including a Board of Trustees, Volunteers, Chief Executive, Global Executive Director, Finance Manager, Office Manager, 2 Care Coordinators, Transition Coordinator, Community Inclusion Coordinator, Community Outreach Coordinator, Patient and Public Involvement & Engagement Coordinator and a Wellbeing Coordinator.

In May 2023, ASUK celebrated our 25th anniversary and we took the time to reflect on how far the charity has developed over the years. We are proud of all that we have achieved and will always be forever grateful to the families, professionals, funders and collaborators that have supported us along the way. The health and wellbeing of people living with Alström Syndrome (AS) will always remain at the heart of everything we do.

The Family Support Team provides a flexible and inclusive package of support for individuals and families living with AS. We have a diverse population with families speaking 17 different languages. On the 31st March 2024, there were 91 people diagnosed with AS in the UK; 54 (59%) were born male, 37 (41%) born female and 50 (55%) are from an ethnic minority community. We are supporting a small number of refugees who do not have settled status in the UK, living in temporary accommodation. The team has found creative ways to engage with families using a variety of methods and have developed positive relationships. We continue to support the highly specialised clinics and liaise with professionals. We contribute to Education Health and Care Plans, social care assessments, child in need meetings, safeguarding meetings and support families to request specialist services in their local area. Care Coordinators are carrying out home visits in person when needed and engaging with families online and over the phone. We are facilitating peer to peer support and online group sessions. Engagement with families has increased further this year with the introduction of our new Wellbeing Pilot Project.

In July 2023, we introduced the Wellbeing Pilot Project to explore the mental health and wellbeing needs of the AS community. The pilot was delivered by Melissa Crowland who is a qualified Social Worker and Humanistic Therapist. Melissa also has lived experience and has a diagnosis of AS. A summary of the consultations and findings of this pilot study was presented to the ASUK Board of Trustees in March 2024. The decision was made to embed the project within the Family Support Service from 1st April 2024.

We continue to work in partnership with Birmingham Women's and Children's Hospital (BWCH) and the Queen Elizabeth Hospital, Birmingham (QEH) to deliver highly specialised multi-disciplinary clinics. BWCH have received additional funding this year to add an additional 2 virtual clinics per year to help with capacity. ASUK Care Coordinators attend every AS clinic to offer support.

Alström Syndrome UK

Trustees' Report

AS Highly Specialised Clinics during 2023-2024

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

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

Adult Clinics – Queen Elizabeth Hospital, Birmingham

- 6 In-Person Clinics
- Additional Outpatient Appointments
- 3 young adults transferred from BWCH to QEH

During the year we received 4 new referrals aged 3, 12, 16 and 27 years. One person sadly passed away, aged 23. 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.

We continue to provide emotional and practical support and there has been a significant increase in the demand on our services due to the 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, and 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 also provided cost of living grants and equipment to support daily living. 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 venturing abroad again and taking part in new adventures. We continue to work with local authorities and different charities to identify opportunities for families to access short breaks, cost-of-living grants and emergency essential food and equipment.

In April 2023, we organised a residential weekend to Whitemoor Lakes, which was a huge success. 9 young people with AS attended with their parents, siblings and carers and were supported by ASUK staff, trustees and volunteers. The weekend was packed full of fun and exciting things to do including canoeing, abseiling, zip wire, challenge course, campfire, games, arts and crafts, plus birthday and anniversary celebrations. We also had a visit from the animal man who brought along a range of animals for families to meet and feel - including a life size interactive dinosaur! The activity was mainly funded through our Children in Need grant with additional funding allocated from general funds. A residential weekend for young people under the age of 8 is planned for April 2024. A huge thank you to Children in Need for providing funding that allows us to run residential weekends plus other activities, events and exciting opportunities for young people such as driving a car and flying an aeroplane!

The ASUK Culture Family Forum continue to meet regularly online and invite guests to discuss specific topics. This year they have interviewed our Chair of Trustees and following feedback, we have introduced a new Trustees of the Future Training Programme that we plan to roll out in September 2024. They have also provided advice and helped with the planning of the ASUK conference which will take place in West Bromwich in October 2024. Members of the Culture Family Forum and other young people, adults, parents and carers will have a much more active role in the conference as they will be interviewing clinicians and researchers about the things that are important to them.

Alström Syndrome UK

Trustees' Report

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 108,357 visits to the ASUK website with 67,083 unique visitors. We reached 10,440 people on the ASUK Facebook page and had 24,594 impressions on X (previously Twitter).

We continue to work internationally through AS Global. We have run 7 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. We held a virtual conference in January 2024 which included 55 attendees from 16 countries. We provided 1 AS Lecture and 1 heart series podcast. We have people from over 100 countries visiting the AS Global page each month.

The BDB network has now grown to over 70 organisations providing 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, marginalised and underserved communities who are affected by rare and genetic conditions. We create safe spaces for learning and collaboration, deliver training and run a community outreach project. We unite and strive for equitable access to services and support for all. During the year we had 112,196 visits to the BDB website with 3,537 unique visitors. We had 46,458 impressions on the BDB X account (previously Twitter).

Following on from last year, we continued our partnership with the Department of Health & Social Care to run another 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.

With the support of the BDB Experts by Experience Advisory Group and our youth and young adult advisors, we updated T-KASH (Transition – Knowledge And Skills in Healthcare). We have created brand new resources, including an animation that is being used throughout the BDB network and beyond. These resources were launched in September 2023, and we have received excellent feedback. The 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. A huge thank you to Contact and The Pears Foundation for funding this work.

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.

Research

AS research is happening around the UK in pockets, including in Edinburgh, Birmingham and at Keele University. We will be asking researchers to provide an update at the ASUK conference in October 2024. We will also request updates from members of the Medical and Scientific Advisory group.

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Trustees' Report

There has been a significant investment in rare disease research, and we are pleased to be part of various successful funding applications for research projects funded by LifeArc, the National Institute for Health and Care Research, the Medical Research Council and Genomics England. We will be supporting patient and public involvement and engagement for a centre to accelerate clinical trials for people living with rare conditions, a project looking at clinical trial designs, the evaluation of The Generation Study and the evaluation of the UK Rare Diseases Framework. In December 2023 we were also successful with a bid to Genomics England to support them to develop a project on Equity in Health Research.

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 and to support with the cost of living
- Provided **4** 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 over **70** organisations
- Delivered Equity, Diversity and Inclusion training events for the BDB network
- Developed new global connections and established partnerships
- Encouraged worldwide completion of the Patient Registry
- Hosted a Global Alström Conference with **55** attendees from **16** different countries bringing together the Alström community from around the world
- Attended the ASI conference in Baltimore, USA and collaborated with AS International, Italy and Germany to help deepen ties with AS organisations and people with lived experience worldwide
- Improved communications & increased our reach - the ASUK website had **108,357** views
- Increased awareness and extended our reach using multimedia communication channels
- Delivered **6** presentations about AS, ASUK and BDB – including presentations at the Medics for Rare Diseases Communication and Inclusivity Conference and the Rare Disease Research UK conference
- Active engagement in successful rare disease research funding applications
- Provided the secretariat for Alström Europe (ASEU)
- 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

Alström Syndrome UK

Trustees' Report

Future aims

The Board of ASUK is committed to continuing our grants programme and to provide support, activities, equipment and events for children, young people, adults, families and carers.

We are looking forward to bringing everyone together again at the ASUK conference in October 2024. This will be the first in person conference since the pandemic. We will take the opportunity to share information, listen to and learn from the AS community. We will use the information we gather to develop our new strategy, making sure our work continues to be driven by the needs of people with lived experience.

We are excited to be part of new rare disease research initiatives and look forward to seeing how each project develops. Having an active role in rare disease research creates opportunities to further our knowledge and hopefully improve health outcomes for people living with AS. BDB is helping us to have more of an active role in research, make new connections and enabling us to forge new collaborations.

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

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

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

Chair's Review

The charity has had a successful year maintaining its financial sustainability and being involved in ongoing support to the community and developing new projects.

We have recruited 1 new Trustee Tarek Hiwot, who compliments the Board members who provide a diverse range of experience and knowledge to the charity. Melissa Crowland left the Board to become a member of staff to lead our new health and wellbeing part of the charity.

We continue to offer both emotional and practical support to individuals and families. Including support at hospital clinics, group sessions and small financial grants.

The BDB membership continues to grow and we are involved with training, research and patient and public involvement.

Our engagement with research projects is increasing and we are able to offer our unique input and knowledge to a variety of work.

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

We had a very successful global conference with representation from across the UK and many countries across the world – it was a great opportunity to share learning and knowledge. Our programme of global webinars, liaison with the other AS organisations worldwide, and attendance at international events has helped build and strengthen relationships across the global community.

The charity goes from strength to strength and I would like to take this opportunity to thank the Chief Executive and all of the Board members for their tireless work and commitment to our community and the team at ASUK who are a pleasure to work with.

Alström Syndrome UK

Trustees' Report

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.

Regards

Sharon Bates

Chair of the Board of Alström Syndrome UK

Financial Review

The General Fund had a surplus of £4,521 and stands at £202,106 (2023 £197,585).

The Trustees hold various designated and restricted funds, which are described in more detail in the next section.

The Trustees made grants of £6,549 from the Financial Assistance Grant Fund and £2,000 from the Adult Empowerment Grant Fund. The Trustees hold total designated funds of £45,842 (2023 £56,293)

The restricted funds stand at £43,611 (2023 £24,000).

Reserves Policy and Going Concern

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

Financial Assistance Grant Fund £8,038 - Amount set aside to provide financial support to AS patients, and their families based upon an assessment of need.

Adult Empowerment Grant Fund £15,618 - 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 £2,186 – represent the fixed assets and cannot be used to fund expenditure unless the assets are sold.

The remaining reserves of £202,106 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.

Management of Risk

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

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

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

Alström Syndrome UK

Trustees' Report

Statement of trustees' responsibilities

The trustees (who are also the directors of Alström Syndrome UK for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland". The report and accounts have been prepared in accordance with the provisions in the Companies Act 2006 relating to small companies.

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including its income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards, comprising FRS 102 have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records that can disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

The annual report was approved by the trustees of the charity on 4th December 2024 and signed on its



Sharon Bates
Trustee

Alström Syndrome UK

Independent Examiner's Report to the trustees of Alström Syndrome UK ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2024.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts 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 your 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.

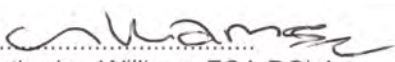
Independent examiner's statement

Since the Company'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 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 Alström Syndrome UK as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts 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 accounts 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

Date: 5th December 2024

Alström Syndrome UK

Statement of Financial Activities for the Year Ended 31 March 2024 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2024 £	Total 2023 £
Income and Endowments from:					
Donations and legacies	3	3,976	-	3,976	3,712
Charitable activities	4	202,563	145,500	348,063	366,290
Investment income	5	2,627	-	2,627	766
Total income		<u>209,166</u>	<u>145,500</u>	<u>354,666</u>	<u>370,768</u>
Expenditure on:					
Raising funds	6	(216)	-	(216)	(216)
Charitable activities	7	<u>(214,880)</u>	<u>(125,889)</u>	<u>(340,769)</u>	<u>(364,620)</u>
Total expenditure		<u>(215,096)</u>	<u>(125,889)</u>	<u>(340,985)</u>	<u>(364,836)</u>
Net (expenditure)/income		<u>(5,930)</u>	<u>19,611</u>	<u>13,681</u>	<u>5,932</u>
Net movement in funds		(5,930)	19,611	13,681	5,932
Reconciliation of funds					
Total funds brought forward		<u>253,878</u>	<u>24,000</u>	<u>277,878</u>	<u>271,946</u>
Total funds carried forward	20	<u>247,948</u>	<u>43,611</u>	<u>291,559</u>	<u>277,878</u>

All of the charity's activities derive from continuing operations during the above two periods.
The funds breakdown for 2023 is shown in note 20.

The notes on pages 13 to 24 form an integral part of these financial statements.

Alström Syndrome UK

(Registration number: 3557191)
Balance Sheet as at 31 March 2024

	Note	2024 £	2023 £
Fixed assets			
Tangible assets	14	2,186	4,088
Current assets			
Debtors	15	42,071	38,613
Investments	16	85,000	85,000
Cash at bank and in hand	17	194,981	171,612
		<u>322,052</u>	<u>295,225</u>
Creditors: Amounts falling due within one year	18	<u>(32,679)</u>	<u>(21,435)</u>
Net current assets		<u>289,373</u>	<u>273,790</u>
Net assets		<u>291,559</u>	<u>277,878</u>
Funds of the charity:			
Restricted income funds			
Restricted funds		43,611	24,000
Unrestricted income funds			
Unrestricted funds		<u>247,948</u>	<u>253,878</u>
Total funds	20	<u>291,559</u>	<u>277,878</u>

For the financial year ending 31 March 2024 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 charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

The financial statements on pages 11 to 24 were approved by the trustees, and authorised for issue on 4th December 2024 and signed on their behalf by:



Sharon Bates
Trustee

The notes on pages 13 to 24 form an integral part of these financial statements.

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

1 Charity status

The charity is limited by guarantee, incorporated in England & Wales, and consequently does not have share capital. Each of the members is liable to contribute an amount not exceeding £10 towards the assets of the charity in the event of liquidation.

The address of its registered office is:

4 St Kitts Close
Torquay
Devon
TQ2 7GD

2 Accounting policies

Summary of significant accounting policies and key accounting estimates

The principal accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all the years presented, unless otherwise stated.

Statement of compliance

The financial statements have been prepared in accordance with 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)) (issued in October 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Basis of preparation

Alstrom Syndrome UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes. The financial statements are prepared in sterling which is the functional currency of the charity.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern nor any significant areas of uncertainty that affect the carrying value of assets held by the charity.

Exemption from preparing a cash flow statement

The charity opted to adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

Income and endowments

All income is recognised once the charity has entitlement to the income, it is probable that the income will be received and the amount of the income receivable can be measured reliably.

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

Donations and legacies

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance by the charity before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that these conditions will be fulfilled in the reporting period.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Tangible fixed assets

Individual fixed assets costing £250 or more are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Computer Equipment	25% straight line

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

Current asset investments

Current asset investments are included at the lower of cost and net realisable value / market value.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Designated funds are unrestricted funds earmarked by the trustees for particular future projects or commitments.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Financial instruments

Classification

Financial assets and financial liabilities are recognised when the charity becomes a party to the contractual provisions of the instrument.

Financial liabilities and equity instruments are classified according to the substance of the contractual arrangements entered into. An equity instrument is any contract that evidences a residual interest in the assets of the charity after deducting all of its liabilities.

Recognition and measurement

All financial assets and liabilities are initially measured at transaction price (including transaction costs), except for those financial assets classified as at fair value through profit or loss, which are initially measured at fair value (which is normally the transaction price excluding transaction costs), unless the arrangement constitutes a financing transaction. If an arrangement constitutes a financing transaction, the financial asset or financial liability is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Financial assets and liabilities are only offset in the statement of financial position when, and only when there exists a legally enforceable right to set off the recognised amounts and the charity intends either to settle on a net basis, or to realise the asset and settle the liability simultaneously.

Financial assets are derecognised when and only when a) the contractual rights to the cash flows from the financial asset expire or are settled, b) the charity transfers to another party substantially all of the risks and rewards of ownership of the financial asset, or c) the charity, despite having retained some, but not all, significant risks and rewards of ownership, has transferred control of the asset to another party.

Financial liabilities are derecognised only when the obligation specified in the contract is discharged, cancelled or expires.

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

3 Income from donations and legacies

	Unrestricted funds £	Total 2024 £
Donations		
General Donations	3,976	3,976
	Unrestricted funds £	Total 2023 £
Donations		
General Donations	3,712	3,712

4 Income from charitable activities

	Unrestricted funds £	Restricted funds £	Total 2024 £
Unrestricted Grants	8,000	-	8,000
Transition Activities	-	24,000	24,000
Breaking Down Barriers	-	113,000	113,000
Pears	-	8,500	8,500
NHS Commissioning	180,089	-	180,089
Sundry income	14,474	-	14,474
	202,563	145,500	348,063
	Unrestricted funds £	Restricted funds £	Total 2023 £
Unrestricted Grants	10,000	-	10,000
Transition Activities	-	22,900	22,900
Breaking Down Barriers	-	132,415	132,415
Pears	-	8,500	8,500
NHS Commissioning	171,061	-	171,061
Sundry income	21,414	-	21,414
	202,475	163,815	366,290

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Notes to the Financial Statements for the Year Ended 31 March 2024

5 Investment income

	Unrestricted funds £	Total 2024 £
Bank interest receivable	2,627	2,627
	Unrestricted funds £	Total 2023 £
Bank interest receivable	766	766

6 Expenditure on raising funds

	Unrestricted funds General £	Total 2024 £
Costs of raising donations and legacies		
Administration costs	216	216
	Unrestricted funds General £	Total 2023 £
Costs of raising donations and legacies		
Administration costs	216	216

7 Expenditure on charitable activities

	Unrestricted funds £	Restricted funds £	Total 2024 £
NHS Commissioning	146,539	-	146,539
Transition Activities	-	19,089	19,089
Breaking Down Barriers	-	100,660	100,660
Pears	-	6,140	6,140
Financial Assistance Grant Fund	6,549	-	6,549
Adult Empowerment Grant fund	2,000	-	2,000
Fixed assets	1,902	-	1,902
Support costs	57,890	-	57,890
	214,880	125,889	340,769

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

		Unrestricted funds £	Restricted funds £	Total 2023 £
NHS Commissioning		138,072	-	138,072
Transition Activities		-	26,114	26,114
Breaking Down Barriers		-	122,683	122,683
Pears		-	7,940	7,940
Family Support		-	3,054	3,054
Financial Assistance Grant Fund		4,990	-	4,990
Adult Empowerment Grant fund		1,000	-	1,000
Fixed assets		1,944	-	1,944
Support costs	8	58,823	-	58,823
		<u>204,829</u>	<u>159,791</u>	<u>364,620</u>

8 Analysis of support costs

Support costs allocated to charitable activities

	Support costs £	Total 2024 £	Total 2023 £
Staff costs	30,083	30,083	43,275
Membership fees	605	605	334
Sundry expenses	8,747	8,747	2,669
Telephone	385	385	984
Insurance	1,203	1,203	909
Accountancy fees	1,251	1,251	1,164
Contractors fees	6,435	6,435	5,990
Hotels, travelling and subsistence costs	1,543	1,543	1,774
Printing, postage, stationery and advertising	71	71	624
Conferences	7,567	7,567	1,100
	<u>57,890</u>	<u>57,890</u>	<u>58,823</u>

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

9 Net incoming/outgoing resources

Net incoming resources for the year include:

	2024 £	2023 £
Depreciation of office equipment	<u>1,902</u>	<u>1,944</u>

10 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

During the year, Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustee meetings, conference and project costs these claims totalled £7,721 (2023 £1,037). Costs have increased 2024 due to a trustee attending the ASI Conference in the USA and expenses connected with the Wellbeing Project.

11 Staff costs

The aggregate payroll costs were as follows:

	2024 £	2023 £
Staff costs during the year were:		
Wages and salaries	202,101	206,107
Social security costs	13,489	14,574
Pension costs	10,195	9,432
Other staff costs	<u>4,416</u>	<u>4,093</u>
	<u>230,201</u>	<u>234,206</u>

The average head count of employees during the year was 8 (2023: 8). The average number of full-time equivalent employees during the year is analysed as follows:

	2024 No	2023 No
Staff	<u>5</u>	<u>6</u>

No employee received emoluments of more than £60,000 during the year.

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

12 Independent examination fees

	2024 £	2023 £
Independent examination of the financial statements	2,502	2,328
Other services	-	2,000
	<u>2,502</u>	<u>4,328</u>

13 Taxation

The charity is a registered charity and is therefore exempt from taxation.

14 Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2023	<u>13,012</u>
At 31 March 2024	<u>13,012</u>
Depreciation	
At 1 April 2023	8,924
Charge for the year	<u>1,902</u>
At 31 March 2024	<u>10,826</u>
Net book value	
At 31 March 2024	<u>2,186</u>
At 31 March 2023	<u>4,088</u>

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Notes to the Financial Statements for the Year Ended 31 March 2024

15 Debtors

	2024 £	2023 £
Trade debtors	18,507	21,150
Prepayments	23,564	17,463
	<u>42,071</u>	<u>38,613</u>

16 Current asset investments

	2024 £	2023 £
Deposits	<u>85,000</u>	<u>85,000</u>

17 Cash and cash equivalents

	2024 £	2023 £
Cash at bank	<u>194,981</u>	<u>171,612</u>

18 Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	7,765	541
Other taxation and social security	14,170	13,241
Accruals	10,744	7,653
	<u>32,679</u>	<u>21,435</u>

19 Pension and other schemes

Defined contribution pension scheme

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £10,195 (2023: £9,432).

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

20 Funds

	Balance at 1 April 2023 £	Incoming resources £	Resources expended £	Balance at 31 March 2024 £
Unrestricted funds				
General Funds	197,585	209,166	(204,645)	202,106
Financial Assistance Grant Fund	14,587	-	(6,549)	8,038
Adult Empowerment Grant Fund	17,618	-	(2,000)	15,618
Fixed Assets	4,088	-	(1,902)	2,186
Research Fund	20,000	-	-	20,000
	<u>253,878</u>	<u>209,166</u>	<u>(215,096)</u>	<u>247,948</u>
Restricted funds				
Children in Need	2,755	24,000	(19,089)	7,666
Breaking Down Barriers	20,685	113,000	(100,660)	33,025
Pears	560	8,500	(6,140)	2,920
	<u>24,000</u>	<u>145,500</u>	<u>(125,889)</u>	<u>43,611</u>
Total funds	<u>277,878</u>	<u>354,666</u>	<u>(340,985)</u>	<u>291,559</u>
	Balance at 1 April 2022 £	Incoming resources £	Resources expended £	Balance at 31 March 2023 £
Unrestricted funds				
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>253,878</u>
Restricted funds				
Children in Need	5,969	22,900	(26,114)	2,755
Breaking Down Barriers	10,953	132,415	(120,447)	22,921
Smaller Restricted Funds	3,054	-	(3,054)	-
Pears	-	8,500	(7,940)	560
	<u>19,976</u>	<u>163,815</u>	<u>(157,555)</u>	<u>26,236</u>
Total funds	<u>271,946</u>	<u>370,768</u>	<u>(362,600)</u>	<u>280,114</u>

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

Unrestricted Funds

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 Alstrom patients and their families based upon an assessment of need.

Adult Empowerment Grant Fund

Amount set aside to enable and empower adults with Alstrom 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 Alstrom.

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 Alstrom Syndrome.

Restricted Funds

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.

21 Analysis of net assets between funds

	Unrestricted funds General £	Restricted funds £	Total funds at 31 March 2024 £
Tangible fixed assets	2,186	-	2,186
Current assets	267,774	54,278	322,052
Current liabilities	(22,012)	(10,667)	(32,679)
Total net assets	<u>247,948</u>	<u>43,611</u>	<u>291,559</u>

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2024

	Unrestricted funds General £	Restricted funds £	Total funds at 31 March 2023 £
Tangible fixed assets	4,088	-	4,088
Current assets	265,454	29,771	295,225
Current liabilities	<u>(15,664)</u>	<u>(5,771)</u>	<u>(21,435)</u>
Total net assets	<u>253,878</u>	<u>24,000</u>	<u>277,878</u>

22 Related party transactions

There were no related party transactions in the year.