

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 2025



Alström Syndrome UK

Reference and Administrative Details

Trustees: Prof Timothy Barrett
Sharon Bates
Jane Biglin
Haris Hamid
Tarekegn Hiwot
Alexandra Line (appointed 1 April 2024)
Trevor Parkin
Carol Prescott
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 2025.

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.

ASUK Board of Trustees

- Sharon Bates (Chair), appointed on 2nd November 2019
- Tim Barrett, appointed on 2nd November 2019
- Haris Hamid, appointed on 9th March 2022
- Carol Prescott, appointed on 9th March 2022
- Jane Biglin, appointed on 18th July 2022
- Mathilde Yates (Treasurer), appointed on 18th July 2022
- Trevor Parkin (Vice-chair), appointed on 21st June 2023
- Tarekegn Hiwot, appointed on 23rd November 2023
- Alex Line, appointed on 1st April 2024

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Trustees' Report

OBJECTIVES AND ACTIVITIES

Public benefit

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

Purposes and aims

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

To promote the health and wellbeing of people with Alström Syndrome - particularly (but not exclusively) through the provision of awareness raising, support, advice and information for people living with Alström Syndrome, their families, carers and those working with them.

1. To promote the health and wellbeing of people with Alström Syndrome - particularly (but not exclusively) through the provision of awareness raising, support, advice and information for people living with Alström Syndrome, their families, carers and those working with them.
2. To promote research into Alström Syndrome and related conditions in the UK and abroad and disseminate the results to the public.

ACHIEVEMENTS AND PERFORMANCE

Alström Syndrome UK (ASUK) has a skilled and experienced team including a Board of Trustees, Volunteers, Chief Executive, Finance Manager, Operations Manager, 2 Care Coordinators, Transition Coordinator, Community Inclusion Coordinator, Wellbeing Coordinator and Lived Experience Coordinator.

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.

On the 31st March 2025, we know of 94 people diagnosed with AS in the UK (1 in Scotland, 5 in Wales and 88 in England). 61% of people were born male and 39% born female. 43% are under the age of 18 years. 55% of people are from an ethnic minority community and the AS community speaks 17 different languages.

AS is an ultra-rare, complex and life limiting condition. The condition brings many challenges and people living with AS often find themselves trying to navigate complex health, education, work, social care and benefits systems. People often require emotional, practical and financial support. ASUK helps individuals and families to understand and manage the condition and overcome many of the barriers they face when accessing services and support.

The ASUK Family Support Service provides support to people diagnosed with AS and to their parents, carers, partners, siblings and wider family members. The ASUK team provides person-centred 1:1 support, information and advice, signposting for further support from other individuals/organisations, knowledge and understanding of the impact of living with AS and hope through research.

We provide the following:

- Health and wellbeing support
- Clinic support and coordination
- Advocacy
- Home and school visits

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- Telephone/online support
- Support throughout transition
- Contribute to assessments including education and social care provision, benefit claims
- Support through Tribunals
- Provide grants
- Provide activities and equipment
- Produce a Medical Handbook and Clinical Guidelines with support from specialist clinicians
- Website
- Webinars
- Research opportunities
- Opportunities to join lived experience advisory groups / peer-peer support groups
- Trustees of the Future Mentorship

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. ASUK Care Coordinators attend every AS clinic to offer support.

AS Highly Specialised Clinics during 2024-2025

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
- 4 young adults transferred from BWCH to QEH

During the year we received 6 new referrals aged 2 months, 7, 2x18, 28 and 35 years. 3 people sadly passed away, aged 4 months, 24, and 35 years. We continue to support bereaved families and the AS community as best we can. Losing members of the AS community is devastating and impacts all of us.

We continue to provide emotional and practical support and the introduction of our new Wellbeing Service has been welcomed by our community.

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 equipment to support daily living. Through our Adult Empowerment grants, we have provided funding for people over the age of 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 experiencing new adventures and having fun while also becoming more active and taking part in exercise. We provided 15 grants in total throughout the year.

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We continue to work with local authorities and different charities to identify opportunities for individuals and families to access short breaks, cost-of-living grants and emergency essential food and equipment.

Last year we ran a residential weekend for children aged 8 years and over. This year we ran a residential weekend for children aged 8 years and under (plus any child who missed out on last year's activities) accompanied by their siblings of any age and their parents/carers. This exciting weekend included a trip to Ash End Farm, music making activity, Dippy the clown show, circus skills and balloon modelling. It was filled with fun and laughter with everyone making new friends. This residential activity was made possible through funding from Children in Need. This was the final year of a 3-year grant and the outcomes we have been working towards are:

- Improved social interactions
- Improved healthy lifestyles and choices
- Increased resilience to cope with key changes in life (Transition)

The funding also enabled us to run a Foodie Active Friends Club. These sessions were run alongside clinics to provide social activities, fun, games and information sessions - including healthy eating and oral health using tactile resources which are helpful for children and young people with sight loss.

This grant has enabled us to organise some fabulous activities and events. It has been wonderful to see the difference this funding and these opportunities have made for children, young people and their families. We are very grateful to Children in Need and although our recent grant application was unsuccessful, we hope to be able to apply again soon.

In October we held our ASUK 'Together Again' conference. The event brought families and professionals together again for the first time since 2019, when Covid hampered our efforts to be together in person. This was a great opportunity to explore the latest research and clinical developments and share our lived experiences and top tips. The conference took place in the West Midlands and while parents and carers took part in the conference, children and young people had a fun filled day out at Drayton Manor theme park. Our Medical and Scientific Advisory Group also took this opportunity to meet and discuss research opportunities which have led to exciting new opportunities in 2025/26.

The ASUK Culture Family Forum (CFF) continue to meet monthly online and invite guests to discuss specific topics. This year they have interviewed ASUK Care Coordinators and a researcher who is using frogs and tadpoles to do research into AS. The CFF had an active role in the conference, they helped with planning the event, one person recorded an interview online with a clinician that was played during the conference and two CFF members spoke at the conference about their experiences of being part of the group. This was a highlight of the conference, especially when one of the young people stood up and sang a song which everyone then joined in with.

During meetings, CFF members shared their thoughts, ideas and experiences on a range of different topics including moving to residential college, how to improve clinic appointments, useful technology for people with sight and hearing loss and cooking tips. They have also done book reviews and tried out new equipment and provided feedback to the group on items such as Ramble Tags to support guided running and walking. They also take time in each meeting just to have a general catch up as friends.

One of the CFF members stood down from the group to start her ASUK Trustees of the Future Training Programme which is going very well.

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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 160,000 visits to the ASUK website with 107,000 unique visitors. We reached 53,316 people on the ASUK Facebook page and had 10,000 impressions on X.

We continue to work internationally through AS Global. We have run 1 Welcome to Wellbeing Webinar and 1 Technology and Apps Webinar 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 delivered 1 AS Lecture and had people from over 100 countries visiting the AS Global page each month.

The BDB network has now grown to 77 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, contribute to research and run a community outreach project. We unite and strive for equitable access to services and support for all. During the year we had 170,000 visits to the BDB website with 122,000 unique visitors.

We have continued our partnership with the Department of Health & Social Care and this year we ran a workshop with our BDB Experts by Experience Advisory Group. The aim of the workshop was to gather views on the governments new 10-year Health Plan and to explore the three shifts – Analogue to Digital, Hospital to Community and Treatment to Prevention. We particularly focussed on the potential impact for people from diverse, marginalised and underserved communities who live with rare conditions. Here is a link to the workshop report [The 10 Year Health Plan Workshop, Report | Breaking Down Barriers](#)

We have continued to share our T-KASH resources (Transition, Knowledge and Skills in Healthcare). These are now being used within the wider rare disease community and beyond.

We have continued to work more broadly within the rare disease community, in the UK and across the globe. 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

The ASUK conference helped reinforce the need for more research. We were joined at the conference by scientists and clinicians who have an interest in AS. Listening to people with lived experience has sparked a determination in them to do more where they can. Following the conference, 2 research applications were submitted for research into AS that will start in 2025/26. ASUK also committed to contribute funding towards a PhD student to support research in AS at Keele University. We look forward to seeing where this research leads and will continue to work together with our Medical and Scientific Advisory Group to push for more research in areas that matter most to people living with AS.

We are pleased to be involved in wider rare disease research through projects funded by LifeArc, the National Institute for Health and Care Research, the Medical Research Council and Genomics England. We are contracted to supporting patient and public involvement and engagement for the LifeArc Acceleration of Rare Disease Trials Centre, the evaluation of The Generation Study and the evaluation of the UK Rare Diseases Framework. We have also supported Genomics England to deliver a project on Equity in Health Research.

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Future aims

In December 2024, ASUK started work on a new Business Plan, supported by the Cranfield Trust. This involved slight changes to our charitable objectives and an update to our vision, mission and values. The ASUK team and Board of Trustees are working together and in consultation with the AS community to identify priorities and to find ways to strengthen the charity and improve sustainability. The new Business plan will be finalised in 2025/26.

ASUK 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.

We look forward to the year ahead.

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 a stable Board of Trustees who bring a breadth of knowledge and experience. Thank you to the Trustees for giving their time and support to 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 projects.

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. I would like to take this opportunity to thank the Chief Executive and our team of staff for all they do.

We held a very successful ASUK conference which brought together families and health professionals for a very informative and fun event.

We have developed our business plan and strategy for the charity to help us prioritise and focus our work so that the charity can continue to go from strength to strength.

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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 £10,634 and stands at £212,740 (2024 £202,106).

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

The Trustees made grants of £5,405 from the Financial Assistance Grant Fund and £2,525 from the Adult Empowerment Grant Fund.

The restricted funds stand at £61,253 (2024 £43,611).

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:

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 £14,000 - Amount set aside to provide financial support to AS patients, and their families based upon an assessment of need.

Activities Fund £6,000 - Amount set aside to provide funds for activities.

Research Fund £40,000 – Amount set aside to fund research into AS.

Fixed Assets Fund £1,553 – represent the fixed assets and cannot be used to fund expenditure unless the assets are sold.

The remaining reserves of £212,740 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.

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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 15 October 2025 and signed on its behalf by:



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 2025.

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 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 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 November 2025

Alström Syndrome UK

Statement of Financial Activities for the Year Ended 31 March 2025 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2025 £	Total 2024 £
Income and Endowments from:					
Donations and legacies	3	4,951	-	4,951	3,976
Charitable activities	4	252,495	119,000	371,495	348,063
Investment income	5	<u>2,942</u>	<u>-</u>	<u>2,942</u>	<u>2,627</u>
Total income		<u>260,388</u>	<u>119,000</u>	<u>379,388</u>	<u>354,666</u>
Expenditure on:					
Raising funds	6	(216)	-	(216)	(216)
Charitable activities	7	<u>(233,827)</u>	<u>(101,358)</u>	<u>(335,185)</u>	<u>(340,769)</u>
Total expenditure		<u>(234,043)</u>	<u>(101,358)</u>	<u>(335,401)</u>	<u>(340,985)</u>
Net income		<u>26,345</u>	<u>17,642</u>	<u>43,987</u>	<u>13,681</u>
Net movement in funds		26,345	17,642	43,987	13,681
Reconciliation of funds					
Total funds brought forward		<u>247,948</u>	<u>43,611</u>	<u>291,559</u>	<u>277,878</u>
Total funds carried forward	20	<u><u>274,293</u></u>	<u><u>61,253</u></u>	<u><u>335,546</u></u>	<u><u>291,559</u></u>

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2024 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 2025

	Note	2025 £	2024 £
Fixed assets			
Tangible assets	14	1,553	2,186
Current assets			
Debtors	15	64,883	42,071
Investments	16	85,000	85,000
Cash at bank and in hand	17	208,502	194,981
		<u>358,385</u>	<u>322,052</u>
Creditors: Amounts falling due within one year	18	<u>(24,392)</u>	<u>(32,679)</u>
Net current assets		<u>333,993</u>	<u>289,373</u>
Net assets		<u>335,546</u>	<u>291,559</u>
Funds of the charity:			
Restricted income funds			
Restricted funds		61,253	43,611
Unrestricted income funds			
Unrestricted funds		<u>274,293</u>	<u>247,948</u>
Total funds	20	<u>335,546</u>	<u>291,559</u>

For the financial year ending 31 March 2025 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 15 October 2025 and signed on their behalf by:



Sharon Bates
Trustee

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

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Notes to the Financial Statements for the Year Ended 31 March 2025

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

These financial statements were authorised for issue by the trustees on 15 October 2025.

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.

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Notes to the Financial Statements for the Year Ended 31 March 2025

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

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Notes to the Financial Statements for the Year Ended 31 March 2025

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 2025

3 Income from donations and legacies

	Unrestricted funds £	Total 2025 £
Donations		
General Donations	4,951	4,951
	Unrestricted funds £	Total 2024 £
Donations		
General Donations	3,976	3,976

4 Income from charitable activities

	Unrestricted funds £	Restricted funds £	Total 2025 £
Unrestricted Grants	3,000	-	3,000
Transition Activities	-	6,000	6,000
Breaking Down Barriers	-	113,000	113,000
NHS Commissioning	187,700	-	187,700
Sundry income	61,795	-	61,795
	<u>252,495</u>	<u>119,000</u>	<u>371,495</u>
	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
	<u>202,563</u>	<u>145,500</u>	<u>348,063</u>

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Notes to the Financial Statements for the Year Ended 31 March 2025

5 Investment income

	Unrestricted funds £	Total 2025 £
Bank interest receivable	<u>2,942</u>	<u>2,942</u>
	Unrestricted funds £	Total 2024 £
Bank interest receivable	<u>2,627</u>	<u>2,627</u>

6 Expenditure on raising funds

	Unrestricted funds General £	Total 2025 £
Costs of raising donations and legacies		
Administration costs	<u>216</u>	<u>216</u>
	Unrestricted funds General £	Total 2024 £
Costs of raising donations and legacies		
Administration costs	<u>216</u>	<u>216</u>

7 Expenditure on charitable activities

	Unrestricted funds £	Restricted funds £	Total 2025 £
NHS Commissioning	170,279	-	170,279
Transition Activities	-	13,666	13,666
Breaking Down Barriers	-	84,772	84,772
Pears	-	2,920	2,920
Financial Assistance Grant Fund	5,405	-	5,405
Adult Empowerment Grant fund	2,525	-	2,525
Fixed assets	1,771	-	1,771
Support costs	45,558	-	45,558
General	<u>8,289</u>	<u>-</u>	<u>8,289</u>
	<u>233,827</u>	<u>101,358</u>	<u>335,185</u>

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Notes to the Financial Statements for the Year Ended 31 March 2025

		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	8	<u>57,890</u>	<u>-</u>	<u>57,890</u>
		<u>214,880</u>	<u>125,889</u>	<u>340,769</u>

8 Analysis of support costs

Support costs allocated to charitable activities

	Total 2025 £	Total 2024 £
Staff costs	29,511	30,083
Membership fees	593	605
Sundry expenses	1,421	8,747
Telephone	175	385
Insurance	1,090	1,203
Accountancy fees	1,314	1,251
Contractors fees	6,449	6,435
Hotels, travelling and subsistence costs	4,903	1,543
Printing, postage, stationery and advertising	75	71
Conferences	<u>27</u>	<u>7,567</u>
	<u>45,558</u>	<u>57,890</u>

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Notes to the Financial Statements for the Year Ended 31 March 2025

9 Net incoming/outgoing resources

Net incoming resources for the year include:

	2025	2024
	£	£
Depreciation of office equipment	<u>1,771</u>	<u>1,902</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 and the ASUK conference these claims totaled £1,733 (2024 £7,721). Costs have decreased from 2024, which included 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:

	2025	2024
	£	£
Staff costs during the year were:		
Wages and salaries	188,447	202,101
Social security costs	12,343	13,489
Pension costs	10,158	10,195
Other staff costs	<u>3,653</u>	<u>4,416</u>
	<u>214,601</u>	<u>230,201</u>

The average head count of employees during the year was 8 (2024: 8). The average number of full-time equivalent employees during the year is analysed as follows:

	2025	2024
	No	No
Staff	<u>5</u>	<u>5</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 2025

12 Independent examination fees

	2025 £	2024 £
Independent examination of the financial statements	<u>2,628</u>	<u>2,502</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 2024	13,012
Additions	<u>1,138</u>
At 31 March 2025	<u>14,150</u>
Depreciation	
At 1 April 2024	10,826
Charge for the year	<u>1,771</u>
At 31 March 2025	<u>12,597</u>
Net book value	
At 31 March 2025	<u>1,553</u>
At 31 March 2024	<u>2,186</u>

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025

15 Debtors

	2025 £	2024 £
Trade debtors	62,564	18,507
Prepayments	<u>2,319</u>	<u>23,564</u>
	<u>64,883</u>	<u>42,071</u>

16 Current asset investments

	2025 £	2024 £
Deposits	<u>85,000</u>	<u>85,000</u>

17 Cash and cash equivalents

	2025 £	2024 £
Cash at bank	<u>208,502</u>	<u>194,981</u>

18 Creditors: amounts falling due within one year

	2025 £	2024 £
Trade creditors	2,569	7,765
Other taxation and social security	14,656	14,170
Accruals	<u>7,167</u>	<u>10,744</u>
	<u>24,392</u>	<u>32,679</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 £10,158 (2024: 10,195).

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025

20 Funds

	Balance at 1 April 2024 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2025 £
Unrestricted funds					
General Funds	202,106	260,388	(224,342)	(25,412)	212,740
Financial Assistance Grant Fund	8,038	-	(5,405)	11,367	14,000
Adult Empowerment Grant Fund	15,618	-	(2,525)	(13,093)	-
Fixed Assets	2,186	-	(1,771)	1,138	1,553
Research Fund	20,000	-	-	20,000	40,000
Activities Fund	-	-	-	6,000	6,000
	<u>247,948</u>	<u>260,388</u>	<u>(234,043)</u>	<u>-</u>	<u>274,293</u>
Restricted funds					
Children in Need	7,666	6,000	(13,666)	-	-
Breaking Down Barriers	33,025	113,000	(84,772)	-	61,253
Pears	<u>2,920</u>	<u>-</u>	<u>(2,920)</u>	<u>-</u>	<u>-</u>
	<u>43,611</u>	<u>119,000</u>	<u>(101,358)</u>	<u>-</u>	<u>61,253</u>
Total funds	<u>291,559</u>	<u>379,388</u>	<u>(335,401)</u>	<u>-</u>	<u>335,546</u>

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025

	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	<u>20,000</u>	<u>-</u>	<u>-</u>	<u>20,000</u>
	<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	<u>560</u>	<u>8,500</u>	<u>(6,140)</u>	<u>2,920</u>
	<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>

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

Amount set aside to fund research into Alstrom Syndrome.

Activities Fund

Amount set aside to provide funds for activities.

Alström Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025

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 2025 £
Tangible fixed assets	1,553	-	1,553
Current assets	294,197	64,188	358,385
Current liabilities	(21,457)	(2,935)	(24,392)
Total net assets	274,293	61,253	335,546
	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	247,948	43,611	291,559

22 Related party transactions

There were no related party transactions in the year.