

ALSTROM SYNDROME UK

England & Wales · Charity number 1071196

Details

Other names AS UK

Status Registered

Legal form Charitable company

Company number [03557191](#)

Registered 1998-08-25

Register [View on the Charity Commission register](#)

Contact

Address The Rectory
Barnstaple Hill
Swimbridge
Barnstaple
Devon
EX32 0PH

Phone 07980122404

Email steve.scofield@alstrom.org.uk

Website www.alstrom.org.uk

Activities

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

Activities: Provides information and support to people living with Alstrom Syndrome (AS) and to their families and service providers working with them. Working with Birmingham Woman's and Children's Hospital and Queen Elizabeth Hospital Birmingham to deliver a highly specialised service. As a patient led organisation , the needs and wishes of people affected by AS remain at the heart of all we do.

Classification

- **How:** Provides Human Resources, Provides Buildings/facilities/open Space, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£379,388	£335,401	-	-
2024-03-31	£354,666	£340,985	-	-
2023-03-31	£370,768	£364,836	-	-
2022-03-31	£300,024	£303,193	-	-
2021-03-31	£375,024	£232,270	-	-

Trustees

Name	Role	Appointed
Sharon Bates	Chair	2019-11-02
Alexandra Rayson Line		2024-04-01
Alisha Sadique		2025-10-15
Carol Prescott		2022-03-09
Haris Hamid		2022-03-09
JANE ELIZABETH Biglin		2022-07-18
Mathilde Victoria Yates		2022-07-18
Prof. Timothy Barrett		2019-11-02
TREVOR PARKIN		2023-06-21
Tarekegn Hiwot		2023-11-23

ALSTROM SYNDROME UK

England & Wales - Charity number 1071196

Accounts

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



WESTCOTTS

CHARTERED ACCOUNTANTS
& BUSINESS ADVISERS

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

Alström Syndrome UK

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

Alström Syndrome UK

Trustees' Report

- 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.

Alström Syndrome UK

Trustees' Report

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.

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 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.

Alström Syndrome UK

Trustees' Report

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.

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 £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.

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 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.

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.

Alström Syndrome UK

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.

Alström Syndrome UK

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

Alström Syndrome UK

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	<u>4,951</u>	<u>4,951</u>
	Unrestricted funds £	Total 2024 £
Donations		
General Donations	<u>3,976</u>	<u>3,976</u>

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>

Alström Syndrome UK

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>

Alström Syndrome UK

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	-	8
	<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	27	7,567
	<u>45,558</u>	<u>57,890</u>

Alström Syndrome UK

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	3,653	4,416
	<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	2,920	-	(2,920)	-	-
	<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><u>277,878</u></u>	<u><u>354,666</u></u>	<u><u>(340,985)</u></u>	<u><u>291,559</u></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	<u>(21,457)</u>	<u>(2,935)</u>	<u>(24,392)</u>
Total net assets	<u>274,293</u>	<u>61,253</u>	<u>335,546</u>

	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	<u>(22,012)</u>	<u>(10,667)</u>	<u>(32,679)</u>
Total net assets	<u>247,948</u>	<u>43,611</u>	<u>291,559</u>

22 Related party transactions

There were no related party transactions in the year.

ALSTROM SYNDROME UK

England & Wales - Charity number 1071196

Accounts

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



WESTCOTTS

CHARTERED ACCOUNTANTS
& BUSINESS ADVISERS

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.

Alström Syndrome UK

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.

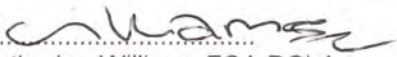
Independent examiner's statement

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
	<u>3,976</u>	<u>3,976</u>
	Unrestricted funds £	Total 2023 £
Donations		
General Donations	3,712	3,712
	<u>3,712</u>	<u>3,712</u>

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
	<u>202,563</u>	<u>145,500</u>	<u>348,063</u>
	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
	<u>202,475</u>	<u>163,815</u>	<u>366,290</u>

Alström Syndrome UK

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	2023
	No	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>

Alström Syndrome UK

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	85,000	85,000

17 Cash and cash equivalents

	2024 £	2023 £
Cash at bank	194,981	171,612

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	(15,664)	(5,771)	(21,435)
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.

ALSTROM SYNDROME UK

England & Wales - Charity number 1071196

Accounts

COMPANY REGISTRATION NUMBER: 3557191
CHARITY REGISTRATION NUMBER: 1071196

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

WESTCOTTS
Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

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

	Pages
Trustees' annual report (incorporating the director's report)	1 to 9
Independent examiner's report to the trustees	10
Statement of financial activities (including income and expenditure account)	11
Statement of financial position	12
Notes to the financial statements	13 to 23

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

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

Reference and administrative details

Registered charity name Alström Syndrome UK

Charity registration number 1071196

Company registration number 3557191

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

The trustees

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

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

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

Recruitment and Appointment of Trustees

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

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

Induction and Training of Trustees

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

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

OBJECTIVES AND ACTIVITIES

Public benefit

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

Objectives and activities Purposes and aims

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

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

ACHIEVEMENTS AND PERFORMANCE

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

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

AS Highly Specialised Clinics during 2022-2023

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

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

Adult Clinics – Queen Elizabeth Hospital, Birmingham

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

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

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

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

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

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

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

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

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

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

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

Key Achievements and Performance

During the year we:

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

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

Research

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

Future aims

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

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

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

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

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

Chairs Review

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

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

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

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

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

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

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

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

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

Kindest Regards

Sharon Bates
Chair of the Board of Alström Syndrome UK

Financial Review

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

The Trustees hold the following designated funds:

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

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

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

Reserves Policy and Going Concern

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

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

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

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

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

Management of Risk

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

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

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

Small company provisions

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

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



Sharon Bates
Trustee

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2023

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

Responsibilities and basis of report

As the trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



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

1st December 2023

Alström Syndrome UK

Company Limited by Guarantee

Statement of Financial Activities (including income and expenditure account)

Year ended 31 March 2023

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

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

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

Alström Syndrome UK
Company Limited by Guarantee
Statement of Financial Position
31 March 2023

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

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

Directors' responsibilities:

- The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476;
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of financial statements.

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

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



Sharon Bates
Trustee

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements

Year ended 31 March 2023

1. General information

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

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Companies Act 2006.

3. Accounting policies

Basis of preparation

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

Going concern

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

Disclosure exemptions

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

Judgements and key sources of estimation uncertainty

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

Fund accounting

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

3. Accounting policies *(continued)*

Incoming resources

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

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

Resources expended

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

3. Accounting policies *(continued)*

Tangible assets

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

Depreciation

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

Computer Equipment - 25% straight line

Financial instruments

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

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

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

Debt instruments are subsequently measured at amortised cost.

Defined contribution plans

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

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

4. Limited by guarantee

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

5. Donations and legacies

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Donations				
General Donations	<u>3,712</u>	<u>3,712</u>	<u>1,449</u>	<u>1,449</u>

6. Charitable activities

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

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

7. Investment income

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Investment income	<u>766</u>	<u>766</u>	<u>411</u>	<u>411</u>

8. Costs of raising donations and legacies

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Administration costs	<u>216</u>	<u>216</u>	<u>216</u>	<u>216</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

9. Expenditure on charitable activities by fund type

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

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

10. Expenditure on charitable activities by activity type

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

11. Analysis of support costs

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

12. Net income/(expenditure)

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

	2023	2022
	£	£
Depreciation of tangible fixed assets	1,944	2,105
Loss on disposal of tangible fixed assets	–	573
	<u>1,944</u>	<u>2,678</u>

13. Independent examination fees

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

14. Staff costs

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

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

14. Staff costs *(continued)*

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

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

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

15. Trustee remuneration and expenses

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

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

16. Tangible fixed assets

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

17. Debtors

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

18. Investments

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

19. Creditors: amounts falling due within one year

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

20. Pensions and other post retirement benefits

Defined contribution plans

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

21. Analysis of charitable funds

Unrestricted funds

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

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

General Fund

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

Financial Assistance Grant Fund

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

Adult Empowerment Grant Fund

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

Fixed Assets

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

Research Fund

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

21. Analysis of charitable funds *(continued)*

Restricted funds

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

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

Children In Need

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

Breaking down Barriers

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

Pears

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2023

22. Analysis of net assets between funds

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

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

23. Related parties

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

ALSTROM SYNDROME UK

England & Wales - Charity number 1071196

Accounts

COMPANY REGISTRATION NUMBER: 3557191
CHARITY REGISTRATION NUMBER: 1071196

Alström Syndrome UK
Company Limited by Guarantee
Unaudited Financial Statements
31 March 2022

WESTCOTTS
Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alström Syndrome UK

Company Limited by Guarantee

Financial Statements

Year ended 31 March 2022

	Pages
Trustees' annual report (incorporating the director's report)	1 to 10
Independent examiner's report to the trustees	11
Statement of financial activities (including income and expenditure account)	12
Statement of financial position	13
Notes to the financial statements	14 to 24

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

The trustees, who are also the directors for the purposes of company law, present their report and the unaudited financial statements of the charity for the year ended 31 March 2022.

Reference and administrative details

Registered charity name Alström Syndrome UK

Charity registration number 1071196

Company registration number 3557191

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

The trustees

Prof. Timothy Barrett	(Appointed 2 November 2019)
Sharon Bates	(Appointed 2 November 2019)
Jane Biglin	(Appointed 18 July 2022)
Melissa Crowland	(Appointed 2 November 2019)
Alexandra Griffiths-Rayson	(Retired 31 March 2022)
Kez Hayat	(Retired 22 October 2022)
Haris Hamid	(Appointed 9 March 2022)
Dr Richard Paisey	(Appointed 7 February 2015)
Trevor Parkin	(Retired 31 March 2022)
Carol Prescott	(Appointed 9 March 2022)
Dr Elena Riva	(Resigned 9 April 2021)
Mathilde Yates	(Appointed 18 July 2021)

Independent examiner Catherine Williams ACA DChA
Westcotts
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

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 ASUK patient advisory or project group after this. The Board actively recruit those who are directly affected by Alström Syndrome 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" 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.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

OBJECTIVES AND ACTIVITIES

Public benefit

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

Objectives and activities

Purposes and aims

Alström Syndrome UK's objectives, as set out in the company's memorandum of association, are;

1. The relief of sickness of persons with Alström Syndrome 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

Public benefit

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

The pandemic has continued to be an incredibly challenging time for all. As lockdown restrictions started to lift, many people within the Alström Syndrome (AS) community found the transition from shielding to going outdoors again very difficult. Our team provided support and offered a person-centred approach for individuals and their families.

Throughout the year we continued to share government guidelines and advice around keeping ourselves and those around us safe. We worked with our team of clinicians to share information about Covid-19 vaccinations and shared links to reliable information so that people could make informed decisions and get access to vaccinations as soon as possible. We also continued to work with service providers to ensure people had access to local support and shared information about any financial benefits and grants available for families.

Following consultation with the AS community, we started to offer a range of in-person, telemedicine, and hybrid clinics in Birmingham. Many people were concerned about the lack of medical tests and face to face consultations throughout the pandemic and were thankful to have the opportunity to be reviewed in person again. Some people were still too anxious about visiting the hospital, using public transport and staying in hotels due to the ongoing risks of Covid-19 and were thankful to continue having the option of a virtual consultation.

We held a successful in-person transfer clinic where five young adults were eventually able to transfer from the paediatric clinic to the adult clinic. Our team continued to support and attend each in-person or virtual clinic and we are proud that we have managed to maintain our record of 100% attendance. We are grateful to the clinicians for the flexibility and support they have provided throughout such challenging times.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

We have restructured the ASUK Family Support Service and are pleased to have introduced two new AS Care Coordinators with specific roles and responsibilities. Toni Smith's role is to support with the coordination of the highly specialised clinics and to liaise with individuals, families, specialist, and local healthcare service providers. Sarah Oliver's role is to liaise with individuals, families and education and social care providers. Sarah also contributes and supports individuals with assessments and benefit claims. Both Care Coordinators are available to carry out home visits and encourage and support people to apply for grants.

The Family Support team have continued to work virtually and in person with a range of professionals and have successfully challenged decisions around support and specialist assessments. We have supported young people as they made the transition between school, college and university to ensure the right support and provision is in place.

We have provided small grants to help promote health and wellbeing, including trampolines, exercise bikes, treadmills and gym memberships.

We were pleased that our grant application to BBC Children in Need was successful, and this will enable us to continue our transition project for a further 3 years which is led by Marie McGee, ASUK National Transition Coordinator. Through this funding, we have provided activities such as driving a car, driving a fire engine, day trips and theatre trips.

The funding we received from the Pears Foundation and the Department for Culture, Media and Sport's Community Match Challenge (as part of the Government's emergency response to COVID-19) enabled us to provide picnic packs to individuals and families of all ages to help them to enjoy the outdoors again. As we emerged from lockdown, families chose to picnic in their own gardens or ventured further afield to enjoy their picnics in open spaces and fresh air.

A new year's gift was sent to everyone in the UK with Alström Syndrome that we know; thanks to an inspired recommendation from our young person's group – The Culture Sparkle Sisters. The group had been reviewing clay kits and they found it so enjoyable, that they wanted to recommend that every young person diagnosed with AS should receive a kit. Listening carefully to the recommendation, the Board agreed that each child and young person would receive play doh, clay kit or voucher (depending on age and accessibility) and each adult would receive a fruit and veg hamper. The Board received some lovely feedback for these welcomed gifts and we are very grateful for the feedback and recommendation from The Culture Sparkle Sisters.

The Culture Sparkle Sisters met regularly online throughout the year and invited guests to discuss specific topics. Adults also met online for 'Time to Talk' sessions where they had a general catch up and offered peer to peer support. We are very grateful to Melissa and Alex for helping to organise and support both groups.

We have continued to work more broadly within the rare conditions community as we recognise that as a small organisation, we are much stronger when working together with others.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

Our application to be a patient representative on the Rare Diseases Framework Delivery Group for England was successful and we were involved in the development of England's Action Plan to address four key priorities for people affected by rare conditions:

- Helping patients get a final diagnosis faster
- Increasing awareness of rare diseases amongst healthcare professionals
- Better coordination of care
- Improving access to specialist care, treatments and drugs

As part of our Breaking Down Barriers (BDB) project, we worked in partnership with the Department of Health & Social Care to run a workshop to understand the health inequalities experienced by people from diverse and marginalised communities who are also affected by a rare condition. Findings from this workshop were fed into England's Action Plan and health equity was included as an underpinning theme. We also attended a round table meeting chaired by the Health Secretary, Sajid Javid to discuss health disparities, research and innovation within the rare disease community.

The BDB project continues to develop and we are incredibly grateful to the Sylvia Adams Charitable Trust for their generosity and continuous support. This has enabled us to expand the BDB team and we are now offering:

- Support and training to BDB members
- An 'Experts by Experience' patient and public involvement (PPI) advisory group
- A Community Outreach project where we deliver Family, Genes and Health workshops within diverse and marginalised communities
- Involvement in research projects as co-applicants and PPI representatives

Additional funding from The National Lottery enabled us to work in partnership with RareMinds to create mental health resources which we included in a health and wellbeing pack and sent to all BDB members to share with their communities. We delivered training to support individuals and organisations throughout the pandemic and we created an animation to illustrate the work of BDB.

In July, the Board reviewed the strategic position of ASUK and made the decision to create AS Global. Kerry Leeson-Beevers became the Chief Executive of ASUK and Ann Chivers became the Executive Director with responsibility to work across borders. This move highlights the Board's ambitious aim of increasing our reach and collaborating with others across the world to learn more about AS and to create new opportunities.

We have increased our online communications through our websites and social media platforms. We held our second Global conference and have developed a series of webinars to share resources, information, learning and experiences. We have been pleased to identify cohorts of people affected by AS in countries such as China and the Palestinian Territories and we look forward to working together, strengthening these relationships and learning from one another.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

Chairs Review

I am, once again, pleased to present our annual report and accounts for 2021-2022.

This has certainly been a year of endurance and resilience for us all.

In April 2021, the UK government advised that we no longer needed to shield and services began to open. However, as many of us have experienced, the NHS remains stretched and our local services have, for some of us, been difficult to access with long waiting lists.

I remain hopeful that this will improve in the coming year and we are pleased that the Children and Adult Clinic services are progressing back to some normality. We will continue to advocate for face-to-face consultations as this is the preference for many of us in the Alström community. However, we also know that a small number of people would prefer to continue with telemedicine clinics for the time being and we will continue to work with the clinical teams to offer flexibility wherever possible.

Many of us tentatively began to attend in person appointments and we were pleased that some of our young adults could meet face to face as they began their transfer to the adult clinic. Getting together socially before Clinic offers an opportunity to have a proper catch up and chin wag! My thanks go to Marie and the family support team for all their hard work ensuring this ran smoothly.

Even in these most challenging times I am delighted to say that patients have 100% attendance record; clear evidence of how valued multidisciplinary clinics are to all of us and a real tribute to the ASUK team who are busy behind the scenes ensuring everyone can attend.

The Family support team have continued to support families to navigate challenging issues.

They began to renew some of their home visits but we have all remained cautious and the team have continued with safety precautions. We know from your comments that these family visits have been welcomed.

As always, individuals with Alström and their families are at the heart of everything we do and I'm delighted to share with you that we sent out a New Year Gift to everyone. We have also provided activities and picnic packs to support people to enjoy the outdoors again. The Trustees continue to set aside funds to support health and wellbeing through activities and small grants. With funding from Children in Need we have been pleased to develop a mixture of online and face to face activities for children and young people, encouraging them to stay connected.

Tackling health inequalities, highlighted even more by the pandemic, remains an important part of our work. The Breaking Down Barriers (BDB) project continues to develop, reaching more and more organisations supporting people with rare and genetic conditions. We held a virtual BDB conference in June 2021 and received excellent feedback. With funding and support from the Sylvia Adams Charitable Trust, we have been able to expand the BDB team and now have three new members of staff to develop this work even further. Thanks to additional funding from the National Lottery, this also meant we could offer a training package and health and wellbeing resources. Our thanks go to the BDB Advisory Group and to the Sylvia Adams Charitable Trust who have continued to advise, support and fund this important project since it started in 2016. It is great to see the difference this project is making and the opportunities it creates for us to collaborate with others and to influence research and UK policy.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

In 2021 the Board of Trustees of ASUK began a review of the strategic position. The Board were keen to build on the success of the Global Conference and the global patient registry and took the bold step to begin developing global outreach and international collaboration.

We began succession planning for the Board and for changes in staffing. I'm pleased to say this culminated in a smooth handover to our new Chief Executive Kerry as Ann became our new Executive Director with responsibility for our Global work. In addition, I began a handover to one of our Trustees Sharon who became the new Chair of ASUK from April 2022. We were sad to lose Asya from BDB and Carol from the Family Support team but welcomed 2 new Care Coordinators; Toni and Sarah. We successfully recruited 2 new Trustees on the 9th March 2022, Haris Hamid and Carol Prescott, I would like to offer my best wishes to all.

Sadly, this is my last report as Chair of Trustees. I would like to thank my Board members for their tireless work and commitment to our community and the team at ASUK who are truly a delight to work with. As an individual with Alström, I know some of the struggles and challenges and it has been my absolute pleasure to be able to Chair the Board and to see how together we have grown and developed the charity to offer the best possible support to both individuals and their loved ones.

Finally, may I say a heartfelt thank you to you all for your contribution; raising funds and awareness of this ultra-rare condition that is Alström Syndrome. I am very proud to have served as Chair and Treasurer and look forward to continuing to contribute in my new role as a Volunteer Advisor at ASUK.

Best wishes to you all and I hope we all get chance to meet up soon.

Kindest Regards



Trevor Parkin
Chair of the Board of Alström Syndrome UK

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

Key Achievements and Performance

During the year we:

- Maintained our record of 100% attendance at clinics
- Received positive feedback and **100%** of families who completed evaluation forms told us they were 'happy' or 'very happy' with the support from ASUK 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 **7** small health and wellbeing grants to empower people to exercise and develop independence
- Provided virtual and face to face activities and events
- Supported people to enjoy the outdoors again by providing picnic packs
- Encouraged healthy lifestyles through information, support and global webinars
- Increased the Breaking Down Barriers (BDB) Network to **59** organisations
- Developed the BDB 'Would you exclude me?' animation
- Hosted the first BDB virtual conference with **77** attendees
- Delivered **7** BDB webinars and training events
- Developed new global connections
- Encouraged worldwide completion of the Patient Registry
- Hosted the second virtual Global Alström Conference with **82** attendees from **21** different countries, bringing together the Alström community from around the world
- Improved communications & increased our reach - the ASUK website had **77,000** views from **175** different countries
- Increased awareness and extended our reach using multimedia communication channels
- Delivered **17** presentations about Alström Syndrome, ASUK and BDB – including to The Royal College of Medicine, Great Ormond Street Hospital and University College London
- Collaborated with others in the rare disease community to create the Action for Rare Disease Empowerment (ARDEnt) Report – Making the Unseen Seen, Rare Disease and the lessons learned throughout the Covid-19 pandemic
- Provided the secretariat for Alström Europe, as well as serving on the Board
- Achieved a positive outcome from grant applications and demonstrated effective cost control
- Acted prudently and resourcefully to ensure we control expenditure and make the most of income and donations
- Supported the ASUK team

Research

We have reignited the Alström Syndrome Medical and Scientific Advisory Group, chaired by Professor Rick Steeds, Cardiologist for the Alström Adult Service.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

Future aims

We look forward to continuing to develop and improve the support we provide to individuals and families affected by Alström Syndrome. We are keen to expand our team of volunteers and to provide further opportunities to involve people with lived experience and promote peer to peer support.

The Board has set aside additional funds to provide even more grants, activities and events for children, young people, adults, families and carers. We would also like to provide opportunities to bring people together who would like to meet up in person where possible.

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

We plan to launch our AS Awareness Raising campaign to improve and speed up diagnosis and ensure that everyone affected by Alström Syndrome can get access to the support and specialist healthcare services as soon as possible.

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

Continue to strengthen our governance to ensure we have an effective, proactive Board.
Invest and care for our staff team and each other to develop skills, abilities and resilience.

Financial Review

The General Fund had a surplus of £40,331 transfers of £40,798 were made to other funds and stands at £187,743 (2021 £188,210).

The trustees made transfers from the general fund to the following designated funds:

- Fixed Assets £798
- Research Fund £20,000
- Financial Assistance Grant Fund £10,000
- Adult Empowerment Grant Fund £10,000

The trustees made grants of £869 from the Financial Assistance Grant Fund. The trustees hold a total designated funds of £64,227 (2021 £25,021)

The restricted funds stand at £19,976 (2021 £61,884).

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

Reserves Policy and Going Concern

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

Financial Assistance Grant Fund £19,577 - Amount set aside to provide financial support to Alström patients and their families based upon an assessment of need.

Adult Empowerment Grant Fund £18,618 - Amount set aside to enable and empower adults with Alström, to be used for a variety of activities that improve their ability to self-advocate, to meet up with other adults and try something new. Funds may also be used to improve communication and confidence for adults with Alström.

Research Fund £20,000 – Amount set aside to fund research into Alström Syndrome

Fixed Assets Fund £6,032 which cannot be used to fund expenditure without being sold.

The remaining reserves of £187,743 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 NHS England clinic contract
2. The loss of key personnel
3. Failing to secure sufficient funds
4. The Coronavirus was identified at the end of March 2020 and continues to be a risk

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

Small company provisions

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

Independent Examiner

Catherine Williams ACA DChA has been re-appointed as independent examiner for the ensuing year.

The trustees' annual report was approved on 23rd November 2022 and signed on behalf of the board of trustees by:



Sharon Bates
Trustee

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2022

I report to the trustees on my examination of the financial statements of Alström Syndrome UK ('the charity') for the year ended 31 March 2022.

Responsibilities and basis of report

As the trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.


Independent examiner's statement

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.


Catherine Williams ACA DChA
Westcotts
Independent Examiner
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

28th November 2022

Alström Syndrome UK

Company Limited by Guarantee

Statement of Financial Activities (including income and expenditure account)

Year ended 31 March 2022

		2022		2021	
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income and endowments					
Donations and legacies	5	1,449	–	1,449	2,111
Charitable activities	6	188,739	109,425	298,164	372,235
Investment income	7	411	–	411	678
Total income		<u>190,599</u>	<u>109,425</u>	<u>300,024</u>	<u>375,024</u>
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and legacies	8	216	–	216	216
Expenditure on charitable activities	9,10	153,599	149,378	302,977	232,054
Total expenditure		<u>153,815</u>	<u>149,378</u>	<u>303,193</u>	<u>232,270</u>
Net (expenditure)/income		<u>36,784</u>	<u>(39,953)</u>	<u>(3,169)</u>	<u>142,754</u>
Transfers between funds		1,955	(1,955)	–	–
Net movement in funds		<u>38,739</u>	<u>(41,908)</u>	<u>(3,169)</u>	<u>142,754</u>
Reconciliation of funds					
Total funds brought forward		213,231	61,884	275,115	132,361
Total funds carried forward		<u>251,970</u>	<u>19,976</u>	<u>271,946</u>	<u>275,115</u>

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

The notes on pages 14 to 24 form part of these financial statements.

Alström Syndrome UK
Company Limited by Guarantee
Statement of Financial Position
31 March 2022

	Note	2022 £	£	2021 £	£
Fixed assets					
Tangible fixed assets	16		6,032		5,957
Current assets					
Debtors	17	169,356		35,374	
Investments	18	85,000		85,000	
Cash at bank and in hand		143,896		157,201	
		398,252		277,575	
Creditors: amounts falling due within one year	19	132,338		8,417	
			265,914		269,158
Net assets			271,946		275,115
Funds of the charity					
Restricted funds			19,976		61,884
Unrestricted funds			251,970		213,231
Total charity funds	21		271,946		275,115

For the year ending 31 March 2022 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476;
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of financial statements.

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

These financial statements were approved by the board of trustees and authorised for issue on 23rd November 2022, and are signed on behalf of the board by:



Sharon Bates
Trustee

The notes on pages 14 to 24 form part of these financial statements.

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements

Year ended 31 March 2022

1. General information

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

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Companies Act 2006.

3. Accounting policies

Basis of preparation

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

Going concern

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

Disclosure exemptions

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

Judgements and key sources of estimation uncertainty

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

Fund accounting

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

3. Accounting policies *(continued)*

Incoming resources

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

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

Resources expended

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

3. Accounting policies *(continued)*

Tangible assets

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

Depreciation

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

Computer Equipment - 25% straight line

Financial instruments

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

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

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

Debt instruments are subsequently measured at amortised cost.

Defined contribution plans

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

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

4. Limited by guarantee

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

5. Donations and legacies

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Donations			
General donations	<u>1,449</u>	<u>–</u>	<u>1,449</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Donations			
General donations	<u>1,611</u>	<u>500</u>	<u>2,111</u>

6. Charitable activities

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

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Unrestricted	35,200	–	35,200
National Commissioning	165,602	–	165,602
Transition Activities	–	40,070	40,070
Breaking Down Barriers	–	113,494	113,494
Pears	–	11,750	11,750
Other income	6,119	–	6,119
	<u>206,921</u>	<u>165,314</u>	<u>372,235</u>

7. Investment income

	Unrestricted Funds £	Total Funds 2022 £	Unrestricted Funds £	Total Funds 2021 £
Investment income	<u>411</u>	<u>411</u>	<u>678</u>	<u>678</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

8. Costs of raising donations and legacies

	Unrestricted Funds	Total Funds 2022	Unrestricted Funds	Total Funds 2021
	£	£	£	£
Administration costs	216	216	216	216

9. Expenditure on charitable activities by fund type

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

	Unrestricted Funds	Restricted Funds	Total Funds 2021
	£	£	£
National Commissioning	68,042	30,633	98,675
Fixed assets	1,278	–	1,278
Transition Activities	–	26,820	26,820
Breaking Down Barriers	–	70,380	70,380
Financial Assistance Grant Fund	4,668	–	4,668
General fund	795	–	795
Pears	–	6,747	6,747
Support costs	22,691	–	22,691
	<u>97,474</u>	<u>134,580</u>	<u>232,054</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

10. Expenditure on charitable activities by activity type

	Activities undertaken directly	Support costs	Total funds 2022	Total fund 2021
	£	£	£	£
National Commissioning	118,708	–	118,708	98,675
Fixed assets	2,678	–	2,678	1,278
Transition Activities	33,047	–	33,047	26,820
Breaking Down Barriers	106,631	–	106,631	70,380
Financial Assistance Grant Fund	869	–	869	4,668
Support costs	–	31,344	31,344	22,691
General fund	–	–	–	795
Pears	9,700	–	9,700	6,747
	<u>271,633</u>	<u>31,344</u>	<u>302,977</u>	<u>232,054</u>

11. Analysis of support costs

	Support costs	Total 2022	Total 2021
	£	£	£
Staff costs	22,376	22,376	13,499
Governance costs	325	325	284
Sundry Expenses	183	183	197
Telephone and Fax	991	991	748
Insurance	734	734	718
Accountancy fees	1,110	1,110	1,050
Contractors fees	5,600	5,600	6,021
Hotels, traveling and subsistence costs	–	–	159
Printing, postage, stationery and advertising	25	25	15
	<u>31,344</u>	<u>31,344</u>	<u>22,691</u>

12. Net (expenditure)/income

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

	2022	2021
	£	£
Depreciation of tangible fixed assets	2,105	1,278
Loss on disposal of tangible fixed assets	<u>573</u>	<u>–</u>

13. Independent examination fees

	2022	2021
	£	£
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>2,220</u>	<u>2,100</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

14. Staff costs

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

	2022	2021
	£	£
Wages and salaries	182,501	154,371
Social security costs	12,438	10,029
Employer contributions to pension plans	8,074	6,583
Other employee benefits	1,135	1,179
	<u>204,148</u>	<u>172,162</u>

The average head count of employees during the year was 7 (2021: 7). The average number of full-time equivalent employees during the year is analysed as follows:

	2022	2021
	No.	No.
Staff	<u>5</u>	<u>5</u>

No employee received employee benefits of more than £60,000 during the year (2021: Nil).

15. Trustee remuneration and expenses

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

During the year 0 (2021: 0) Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustees meetings. These claims totalled £Nil (2021 £Nil).

16. Tangible fixed assets

	Computer Equipment £
Cost	
At 1 April 2021	11,056
Additions	3,503
Disposals	(1,547)
At 31 March 2022	<u>13,012</u>
Depreciation	
At 1 April 2021	5,099
Charge for the year	2,105
Disposals	(224)
At 31 March 2022	<u>6,980</u>
Carrying amount	
At 31 March 2022	<u>6,032</u>
At 31 March 2021	<u>5,957</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

17. Debtors

	2022	2021
	£	£
Prepayments and accrued income	<u>169,356</u>	<u>35,374</u>

18. Investments

	2022	2021
	£	£
Deposits	<u>85,000</u>	<u>85,000</u>

19. Creditors: amounts falling due within one year

	2022	2021
	£	£
Accruals and deferred income	6,030	4,018
Social security and other taxes	<u>126,308</u>	<u>4,399</u>
	<u>132,338</u>	<u>8,417</u>

20. Pensions and other post retirement benefits

Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £8,074 (2021: £6,583).

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

21. Analysis of charitable funds

Unrestricted funds

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

	At 1 April 2020	Income	Expenditure	Transfers	At 31 March 2021
	£	£	£	£	£
General Funds	82,976	209,210	(91,744)	(12,232)	188,210
Financial Assistance Grant Fund	5,114	–	(4,668)	10,000	10,446
Adult Empowerment Grant Fund	8,618	–	–	–	8,618
Fixed Assets	–	–	(1,278)	7,235	5,957
Research Fund	–	–	–	–	–
	<u>96,708</u>	<u>209,210</u>	<u>(97,690)</u>	<u>5,003</u>	<u>213,231</u>

General Funds

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

Financial Assistance Grant Fund

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

Adult Empowerment Grant Fund

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

Fixed Assets

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

Research Fund

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

21. Analysis of charitable funds *(continued)*

Restricted funds

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

	At 1 April 2020 £	Income £	Expenditure £	Transfers £	At 31 March 2021 £
National Commissioning	30,633	–	(30,633)	–	–
<u>Transition Activities</u>					
Children in Need	1,041	40,070	(26,820)	–	14,291
<u>Sylvia Adams Trust</u>					
Breaking down Barriers	1,425	113,494	(70,380)	–	44,539
<u>Family Support</u>					
Pears	–	11,750	(6,747)	(5,003)	–
Smaller restricted funds	2,554	500	–	–	3,054
	<u>35,653</u>	<u>165,814</u>	<u>(134,580)</u>	<u>(5,003)</u>	<u>61,884</u>

National Commissioning Grant

Funds the service agreement between the Charity and NHS England to maximise access to NHS services and provide support and information to Alström patients and their families.

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.

Children in Need

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

Pears

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

22. Analysis of net assets between funds

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

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Tangible fixed assets	5,957	–	5,957
Current assets	215,691	61,884	277,575
Creditors less than 1 year	(8,417)	–	(8,417)
Net assets	<u>213,231</u>	<u>61,884</u>	<u>275,115</u>

23. Related parties

During the year there were no related party transactions (2021: None)

ALSTROM SYNDROME UK

England & Wales - Charity number 1071196

Accounts

COMPANY REGISTRATION NUMBER: 3557191
CHARITY REGISTRATION NUMBER: 1071196

Alström Syndrome UK
Company Limited by Guarantee
Unaudited Financial Statements
31 March 2021

THOMAS WESTCOTT
Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alström Syndrome UK
Company Limited by Guarantee
Financial Statements
Year ended 31 March 2021

	Pages
Trustees' annual report (incorporating the director's report)	1 to 7
Independent examiner's report to the trustees	8 to 9
Statement of financial activities (including income and expenditure account)	10
Statement of financial position	11
Notes to the financial statements	12 to 21

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

The trustees, who are also the directors for the purposes of company law, present their report and the unaudited financial statements of the charity for the year ended 31 March 2021.

Reference and administrative details

Registered charity name Alström Syndrome UK

Charity registration number 1071196

Company registration number 3557191

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

The trustees

Trevor Parkin	Chair
Alexandra Griffiths-Rayson	Vice Chair
Prof. Timothy Barrett	
Sharon Bates	
Melissa Crowland	
Kez Hayat	
Dr Richard Paisey	
Dr Elena Riva	(Resigned 9 April 2021)

Independent examiner Catherine Williams ACA DChA
Thomas Westcott Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

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 ASUK patient advisory or project group after this. The Board actively recruit those who are directly affected by Alström Syndrome 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" 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.

OBJECTIVES AND ACTIVITIES

Public benefit

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

This has been an exceptional year with most of our members shielding during the pandemic. This has put extreme pressures on individuals and families, ASUK acted quickly and flexible to ensure those affected by Alström Syndrome have been offered the practical and emotional support they need.

In the first few weeks of the lockdown we contacted 95% of patients by telephone, online and email. We identified immediate needs and working with local agencies and others to ensure wrap around services; including liaising with local community organisations to deliver food, medicines and provide guide dog walking.

During the year, we have:

Worked with other agencies to ensure access for families to financial support. Intensive family support continued as patients and families struggled to cope and interpret government guidance for 'vulnerable' adults and children.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

Supported families to access Clinics. ASUK Family Support workers coordinated and supported families with the information technology, and helped many families practice getting online to ensure patients and families were confident to take part in telemedicine Clinics. We achieved 100% attendance at virtual clinics.

Developed top tips for telemedicine clinics, based on the evaluation and feedback from patients and their families.

Contributed to consultations led by NHS England; with Clinicians, families and other patient organisations to discuss the adaptations needed to the Alström Service, to ensure patients were supported.

Developed and organised webinars on a range of topics, including; Healthy Hearts, Managing Diabetes at home, Guidance on Shielding and social webinars. Led by specialist clinicians they offered families some reassurance and an opportunity to 'meet' up with other families online.

Provided webinars on health and wellbeing, which have included presentations from a Cardiologist, Dietician and other specialists with conversations around health and wellbeing exercise and dietary advice whilst shielding.

Through our Family Support team, we continued to work virtually with school staff on Education and Health Care Plans' successfully challenging decisions around support and specialised assessments. We continued to support children and young people going to or returning from School, Colleges and University.

Distributed small grants mainly for exercise equipment and independent living including trampolines, exercise bikes, talking microwaves, garden playhouses, climbing frames, adapted marker penfriend, and adapted measuring jugs.

Continued to represent patient's views as a member of the UK Rare Disease Policy Board, involved in the development and publication of the UK Rare Diseases Framework (Department of Health & Social Care), continuing to ensure patients voices are heard and have an influence on decision making.

We have continued to collaborate with other rare disease organisations, such as Rare Disease UK and the Patient Empowerment Group to hold the government to account throughout the development, implementation and evaluation of rare disease policy.

We continue to work with NHS Commissioners and Clinicians to identify areas for improvement within the highly specialised multi-disciplinary clinics. The Rare Disease Insert identifies 3 key areas that Clinicians must report on each year:

- Every person with a rare disease will have a dedicated person responsible for coordinating their care.
- Every patient with a rare disease will be given an 'alert card', including information about their condition, treatment regime and contact details for the individual expert involved in their care.
- Every child with a rare condition will be transferred to appropriate adult services when they reach the age of 18, even if that adult service is not the commissioning responsibility of NHS England.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

Driven forward the Breaking Down Barriers project, supporting those within the network, as many organisations were forced to furlough staff. Working virtually, we offered opportunities to increase networking and developed topical webinars.

Encouraged patients and families to input their details into the established patient registry.

Increased our online capabilities to enable a significant increase in online communications. The website (our window to the world) continued to expand, receiving over 45,000 unique visitors from over 175 countries

As a result of the dissemination of the Early Years survey results in the UK, the Alström Society in Italy used the findings to conduct their own survey, adding to the collective knowledge and understanding about the experience of families with their under-fives.

Objectives and activities

Purposes and aims

Alström Syndrome UK's objectives, as set out in the company's memorandum of association, are;

1. The relief of sickness of persons with Alström Syndrome 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

Chairs Review

I am pleased to introduce our annual report and accounts for 2020/2021.

This is my fourth review as both Chair and Treasurer of the Board of Trustees at Alstrom Syndrome UK and one I admit, has been one of the most challenging to date.

The past 12 months has been dominated by one subject in the world, that of the global pandemic and the phrase that fills our lives with fear and anxiety..... COVID 19 / CORONA VIRUS.

Like so many of you, I am clinically vulnerable and have lived a life of fear of the outside world, scared to go out, worried for myself and family and friends but so grateful for a voice on the phone or a zoom call just confirming there is life outside, and once normality returns, we shall meet and shake hands even hug perhaps.

It's impossible to believe as you read this that someone doesn't know someone who has been affected, and perhaps sadly even lost someone.

In a year dominated by truthfully one thing, the team at ASUK, led by CEO Ann Chivers and supported by the Board of Trustees, has worked tirelessly to keep information updated to help support families by way of phone and numerous social media channels abreast of the ever-changing rules and guidelines, to help us stay free and safe from the risks of catching COVID-19.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

The virtual world is not new to ASUK and its staff, in fact it's a strength within our organisation, but what has proved difficult and upsetting is not meeting up for so long with our patients and their families and overcoming the obstacles of technology and the challenges of being deaf/blind.

The Board I am so proud to lead, continues to be a mix of patients, family members and professionals, with a tremendous knowledge of Alström Syndrome. This continues, and I hope always will enable the Board to be a truly representative patient led organisation, serving our families and loved ones.

In my last Chairs review we had so many plans but we were just at the very start of the pandemic and so it seemed the whole world stood still. Our attentions concentrated on the here and now, and became impossible to plan too far ahead but we tried where we could. We were able to successfully apply for grants and funding for COVID-19 related support for our families to assist where needed.

We haven't forgotten our plans for outings, activities, and individual challenges, let's just say for reasons beyond our control they're temporarily on hold!!!! But I promise all of you, the ASUK team can't wait to meet up with you and make those wishes come true.

As I said earlier, this has been a very strange and difficult time, there has been a tremendous strain put on our mental health and well-being, but we will all be stronger as we hopefully come out the other side.

Financial position

The trustees are confident that we operate to make effective use of our limited resources. The trustees monitor levels of reserves and planned expenditure closely to ensure that the charity is managing our limited reserves to the best benefit of the Alström family. The board continues to ensure we operate in a compliant manner.

Finally, a huge thank you

I would personally like to thank the Board for their continued commitment, our Chief Executive Ann Chivers, and the staff team for their hard work, enthusiasm, and dedication to making a difference to the lives of people and their loved ones with Alström Syndrome. I would also like to say a wholehearted thank you to the exceptional clinicians and professionals who work tirelessly to encourage and support individuals and families.

The work we all do is making a difference, none of which is possible without the generous support of families and friends, supporters and funders, clinicians and professionals. We are extremely grateful to one and all.

Key Achievements and Performance

During the year we:

- Organised and hosted the first virtual Global Alström Conference; a scientific symposium and family conference with 183 attendees from 23 different countries, bringing together the Alström community from all over the world.
- Worked with Clinicians and Academics to contribute to the Clinical Guidelines published in Orphanet and online in September 2020.

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

- Encouraged diet and exercise. With families and specialist Clinicians developed and sent every family a wellbeing resource pack that included family recipes and exercise routines.
- Continued to review and improve the service at clinics based on patient needs, evaluation, and feedback.
- Acted prudently and resourcefully to ensure we control expenditure and make the most of income and donations.
- Increased awareness and extended our reach using multimedia communications channels.
- Provided information and support to families and individuals newly diagnosed.
- Encouraged healthy lifestyles with children, young people and adults, providing exercise equipment and gym memberships.
- Developed online clubs for young people to meet up in a safe space.
- Expanded the Breaking Down Barriers project to develop capacity to address health inequalities.
- Act as the secretariat for the ASEU Board as well as serving on the Board.

Research

We disseminated the Early Years research project, and the Alström Handbook to be used with patient organisations in Europe, and provide a deeper and wider understanding of the under-fives.

Future aims

There has never been a greater need for the support services for families and individuals affected by Alström Syndrome. It has been a year of uncertainty, worry and anxiety for many of us, we have all been affected by the lock down for COVID 19, however, the Board and staff at ASUK remain tenacious and ambitious and aim to:

Increase awareness, knowledge and understanding about Alström Syndrome.

Work collaboratively with the international community to identify key factors and the touch points of diagnosis to enable earlier diagnosis.

Continue to strengthen our governance to ensure we have an effective, proactive board.

Expand and develop the Breaking Down Barriers project to reach more organisations, learning together and develop good practice models to address health inequalities in the rare disease community.

Identify and develop opportunities for clinical trials,

Invest and care for our staff team and each other to develop skills, abilities and resilience.

Financial Review

The General Fund had a surplus of £105,234 and stands at £188,210 (2020 £82,976). The trustees made grants of £5,946 from their designated grant funds which now stand at a total of £19,064. The trustees have also designated a fund equal to the net book value of fixed assets of £5,957 (2020 £-).

The restricted funds stand at £61,884 (2020 £35,653).

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

Reserves Policy and Going Concern

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

Financial Assistance Grant Fund £10,446 -Amount set aside to provide financial support to Alström patients and their families based upon an assessment of need.

Adult Empowerment Grant Fund £8,618 -Amount set aside to enable and empower adults with Alström, to be used for a variety of activities that improve their ability to self-advocate, to meet up with other adults and try something new. Funds may also be used to improve communication and confidence for adults with Alström.

Fixed Assets Fund £5,957 which cannot be used to fund expenditure without being sold.

The remaining reserves of £188,210 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 NHS England clinic contract
2. The loss of key personnel
3. Failing to secure sufficient funds
4. The Coronavirus was identified at the end of March 2020 and continues to be a risk

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

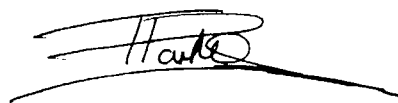
Small company provisions

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

Independent Examiner

Catherine Williams ACA DChA has been re-appointed as independent examiner for the ensuing year.

The trustees' annual report was approved on 8th December 2021 and signed on behalf of the board of trustees by:



Trevor Parkin
Trustee

Alström Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2021

I report to the trustees on my examination of the financial statements of Alström Syndrome UK ('the charity') for the year ended 31 March 2021.

Responsibilities and basis of report

As the trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Alström Syndrome UK

Company Limited by Guarantee

Independent Examiner's Report to the Trustees of Alstrom Syndrome UK
(continued)

Year ended 31 March 2021

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 ACA DChA
Independent Examiner
Thomas Westcott Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

13th December 2021

Alström Syndrome UK

Company Limited by Guarantee

Statement of Financial Activities (including income and expenditure account)

Year ended 31 March 2021

		2021	2020		
		Unrestricted funds	Restricted funds	Total funds	Total funds
	Note	£	£	£	£
Income and endowments					
Donations and legacies	5	1,611	500	2,111	4,556
Charitable activities	6	206,921	165,314	372,235	251,756
Investment income	7	678	–	678	790
Total income		<u>209,210</u>	<u>165,814</u>	<u>375,024</u>	<u>257,102</u>
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and legacies	8	216	–	216	216
Expenditure on charitable activities	9,10	97,474	134,580	232,054	300,453
Total expenditure		<u>97,690</u>	<u>134,580</u>	<u>232,270</u>	<u>300,669</u>
Net income/(expenditure)		<u>111,520</u>	<u>31,234</u>	<u>142,754</u>	<u>(43,567)</u>
Transfers between funds		5,003	(5,003)	–	–
Net movement in funds		<u>116,523</u>	<u>26,231</u>	<u>142,754</u>	<u>(43,567)</u>
Reconciliation of funds					
Total funds brought forward		96,708	35,653	132,361	175,928
Total funds carried forward		<u>213,231</u>	<u>61,884</u>	<u>275,115</u>	<u>132,361</u>

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

The notes on pages 14 to 23 form part of these financial statements.

Alström Syndrome UK
Company Limited by Guarantee
Statement of Financial Position
31 March 2021

	Note	2021		2020	
		£	£	£	£
Fixed assets					
Tangible fixed assets	16		5,957		2,232
Current assets					
Debtors	17	35,374		18,342	
Investments	18	85,000		85,000	
Cash at bank and in hand		157,201		38,727	
		<u>277,575</u>		<u>142,069</u>	
Creditors: amounts falling due within one year	19		8,417		11,940
			<u>269,158</u>		<u>130,129</u>
Net assets			<u>275,115</u>		<u>132,361</u>
Funds of the charity					
Restricted funds			61,884		35,653
Unrestricted funds			213,231		96,708
Total charity funds	21		<u>275,115</u>		<u>132,361</u>

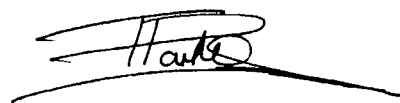
For the year ending 31 March 2021 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476;
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of financial statements.

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

These financial statements were approved by the board of trustees and authorised for issue on 8th December 2021, and are signed on behalf of the board by:



Trevor Parkin
Trustee

The notes on pages 12 to 21 form part of these financial statements.

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements

Year ended 31 March 2021

1. General information

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

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Companies Act 2006.

3. Accounting policies

Basis of preparation

The financial statements have been prepared on the historical cost basis.

Going concern

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

Disclosure exemptions

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

Judgements and key sources of estimation uncertainty

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

Fund accounting

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

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

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

3. Accounting policies *(continued)*

Incoming resources

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

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

Resources expended

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

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

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

Tangible assets

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

3. Accounting policies *(continued)*

Depreciation

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

Computer Equipment - 25% straight line

Financial instruments

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

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

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

Debt instruments are subsequently measured at amortised cost.

Defined contribution plans

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

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

4. Limited by guarantee

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

5. Donations and legacies

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Donations			
General Donations	<u>1,611</u>	<u>500</u>	<u>2,111</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Donations			
General Donations	<u>4,556</u>	<u>–</u>	<u>4,556</u>

6. Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Unrestricted	35,200	–	35,200
NHS Commissioning	165,602	–	165,602
Transition Activities	–	40,070	40,070
Breaking Down Barriers	–	113,494	113,494
Pears	–	11,750	11,750
Other income	<u>6,119</u>	<u>–</u>	<u>6,119</u>
	<u>206,921</u>	<u>165,314</u>	<u>372,235</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Unrestricted	16,542	–	16,542
NHS Commissioning	–	155,047	155,047
Transition Activities	–	19,525	19,525
Breaking Down Barriers	–	35,148	35,148
Pears	–	–	–
Other income	<u>25,494</u>	<u>–</u>	<u>25,494</u>
	<u>42,036</u>	<u>209,720</u>	<u>251,756</u>

7. Investment income

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Investment income	<u>678</u>	<u>678</u>	<u>790</u>	<u>790</u>

8. Costs of raising donations and legacies

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Administration costs	<u>216</u>	<u>216</u>	<u>216</u>	<u>216</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

9. Expenditure on charitable activities by fund type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
NHS Commissioning	68,042	30,633	98,675
Transition Activities	–	26,820	26,820
Breaking Down Barriers	–	70,380	70,380
Financial Assistance Grant Fund	4,668	–	4,668
Adult Empowerment Grant Fund	–	–	–
General fund	795	–	795
Family Support	–	–	–
Research and development	–	–	–
Pears	–	6,747	6,747
Fixed Assets	1,278	–	1,278
Support costs	22,691	–	22,691
	<u>97,474</u>	<u>134,580</u>	<u>232,054</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
NHS Commissioning	–	145,328	145,328
Transition Activities	–	23,255	23,255
Breaking Down Barriers	–	55,143	55,143
Financial Assistance Grant Fund	2,031	–	2,031
Adult Empowerment Grant Fund	5,007	–	5,007
General fund	6,147	–	6,147
Family Support	–	500	500
Research and development	–	20,706	20,706
Pears	–	–	–
Fixed Assets	–	–	–
Support costs	42,336	–	42,336
	<u>55,521</u>	<u>244,932</u>	<u>300,453</u>

10. Expenditure on charitable activities by activity type

	Activities undertaken directly	Support costs	Total funds 2021 £	Total fund 2020 £
NHS Commissioning	98,675	–	98,675	145,328
Transition Activities	26,820	–	26,820	23,255
Breaking Down Barriers	70,380	–	70,380	55,143
Financial Assistance Grant Fund	4,668	–	4,668	2,031
Adult Empowerment Grant Fund	–	–	–	5,007
Support costs	–	22,691	22,691	42,336
General fund	795	–	795	6,147
Fixed Assets	1,278	–	1,278	–
Family Support	–	–	–	500
Research and development	–	–	–	20,706
Pears	6,747	–	6,747	–
	<u>209,363</u>	<u>22,691</u>	<u>232,054</u>	<u>300,453</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

11. Analysis of support costs

	Support costs £	Total 2021 £	Total 2020 £
Staff costs	13,499	13,499	20,167
Governance costs	284	284	435
Sundry Expenses	197	197	73
Telephone and Fax	748	748	592
Depreciation	–	–	408
Insurance	718	718	569
Conference fees	–	–	5,201
Accountancy fees	1,050	1,050	1,435
Contractors fees	6,021	6,021	8,250
Hotels, traveling and subsistence costs	159	159	4,103
Printing, postage, stationery and advertising	15	15	1,103
	<u>22,691</u>	<u>22,691</u>	<u>42,336</u>

12. Net income/(expenditure)

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

	2021 £	2020 £
Depreciation of tangible fixed assets	<u>1,278</u>	<u>1,371</u>

13. Independent examination fees

	2021 £	2020 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>2,100</u>	<u>2,870</u>

14. Staff costs

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

	2020 £	2019 £
Wages and salaries	154,371	170,415
Social security costs	10,029	12,182
Employer contributions to pension plans	6,583	7,065
Other employee benefits	1,179	1,436
	<u>172,162</u>	<u>191,098</u>

The average head count of employees during the year was 6 (2020: 5). The average number of full-time equivalent employees during the year is analysed as follows:

	2021 No.	2020 No.
Staff	<u>5</u>	<u>5</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

14. Staff costs *(continued)*

No employee received employee benefits of more than £60,000 during the year (2020: Nil).

15. Trustee remuneration and expenses

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

During the year 0 (2020: 6) Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustees meetings. These claims totalled £Nil (2020 £1,011).

16. Tangible fixed assets

	Computer Equipment £
Cost	
At 1 April 2020	6,053
Additions	5,003
At 31 March 2021	<u>11,056</u>
Depreciation	
At 1 April 2020	3,821
Charge for the year	1,278
At 31 March 2021	<u>5,099</u>
Carrying amount	
At 31 March 2021	<u>5,957</u>
At 31 March 2020	<u>2,232</u>

17. Debtors

	2021 £	2020 £
Prepayments and accrued income	<u>35,374</u>	<u>18,342</u>

18. Investments

	2021 £	2020 £
Deposits	<u>85,000</u>	<u>85,000</u>

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

19. Creditors: amounts falling due within one year

	2021	2020
	£	£
Accruals and deferred income	4,018	7,086
Social security and other taxes	4,399	4,854
	<u>8,417</u>	<u>11,940</u>

20. Pensions and other post retirement benefits

Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £6,583 (2020: £7,065).

21. Analysis of charitable funds

Unrestricted funds

	At 1 April 2020	Income	Expenditure	Transfers	At 31 March 2021
	£	£	£	£	£
General funds	82,976	209,210	(91,744)	(12,232)	188,210
Financial Assistance Grant Fund	5,114	–	(4,668)	10,000	10,446
Adult Empowerment Grant Fund	8,618	–	–	–	8,618
Fixed Assets	–	–	(1,278)	7,235	5,957
	<u>96,708</u>	<u>209,210</u>	<u>(97,690)</u>	<u>5,003</u>	<u>213,231</u>

	At 1 April 2019	Income	Expenditure	Transfers	At 31 March 2020
	£	£	£	£	£
General funds	85,093	46,582	(48,699)	–	82,976
Financial Assistance Grant Fund	7,145	–	(2,031)	–	5,114
Adult Empowerment Grant Fund	12,825	800	(5,007)	–	8,618
Fixed Assets	–	–	–	–	–
	<u>105,063</u>	<u>47,382</u>	<u>(55,737)</u>	<u>–</u>	<u>96,708</u>

General fund

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

Financial Assistance Grant Fund

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

Adult Empowerment Grant Fund

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

Fixed Assets

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

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

21. Analysis of charitable funds *(continued)*

Restricted funds	At 1 April 2020 £	Income £	Expenditure £	Transfers £	At 31 March 2021 £
NHS Commissioning	30,633	–	(30,633)	–	–
<u>Transition Activities</u>					
Children in Need	1,041	40,070	(26,820)	–	14,291
<u>Sylvia Adams Trust</u>					
Breaking down Barriers	1,425	113,494	(70,380)	–	44,539
<u>Family Support</u>					
Smaller restricted funds	2,554	500	–	–	3,054
Pears	–	11,750	(6,747)	(5,003)	–
<u>Research and development</u>					
One in a million	–	–	–	–	–
	<u>35,653</u>	<u>165,814</u>	<u>(134,580)</u>	<u>(5,003)</u>	<u>61,884</u>

	At 1 April 2019 £	Income £	Expenditure £	Transfers £	At 31 March 2020 £
NHS Commissioning	20,914	155,047	(145,328)	–	30,633
<u>Transition Activities</u>					
Children in Need	4,771	19,525	(23,255)	–	1,041
<u>Sylvia Adams Trust</u>					
Breaking down Barriers	21,420	35,148	(55,143)	–	1,425
<u>Family Support</u>					
Smaller restricted funds	3,054	–	(500)	–	2,554
Pears	–	–	–	–	–
<u>Research and development</u>					
One in a million	20,706	–	(20,706)	–	–
	<u>70,865</u>	<u>209,720</u>	<u>(244,932)</u>	<u>–</u>	<u>35,653</u>

National Commissioning Grant

Funds the service agreement between the Charity and NHS England to maximise access to NHS services and provide support and information to Alström patients and their families

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.

Children in Need

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

Pears

Enabling our team to meet the unprecedented, increasing demand on our support services. The cost of computer equipment £5,003 which has enabled staff to stay connected with vulnerable beneficiaries where face to face contact is inappropriate has been transferred to our fixed asset fund.

One in a Million Fund

A fund established with a long term aim of raising £1 Million for future research into Alström Syndrome.

Alström Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2021

22. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Tangible fixed assets	5,957	–	5,957
Current assets	215,691	61,884	277,575
Creditors less than 1 year	(8,417)	–	(8,417)
Net assets	<u>213,231</u>	<u>61,884</u>	<u>275,115</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Tangible fixed assets	118	2,114	2,232
Current assets	103,817	38,252	142,069
Creditors less than 1 year	(7,227)	(4,713)	(11,940)
Net assets	<u>96,708</u>	<u>35,653</u>	<u>132,361</u>

23. Post balance sheet events

It should be noted that, at the date of preparation of the financial statements, the instability factor relating to the health emergency due to the spread of Coronavirus should not be underestimated. There have been no adjusting events identified whilst preparing the accounts

The charity has reviewed the scenario and evaluated the management actions to mitigate the impact to their operations. The charity has adopted initiatives to safeguard the health of its people and actions aimed at maintaining operational activity. The repercussions on any adjustments to the financial statements are currently not determinable in light of the volatility of the scenario and the continuous evolution of the market, these will be reflected in the 2022 results.

24. Related parties

During the year there were no related party transactions (2020: None)