

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

THOMAS WESTCOTT
Chartered Accountants
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Alström Syndrome UK

Company Limited by Guarantee

Financial Statements

Year ended 31 March 2021

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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
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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 flexibly 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.

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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.

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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.

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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.

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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

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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.

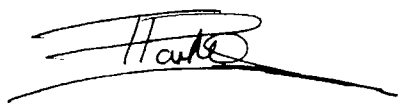
Small company provisions

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

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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

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Statement of Financial Activities (including income and expenditure account)

Year ended 31 March 2021

			2021		2020
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
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	
		277,575		142,069	
Creditors: amounts falling due within one year	19	8,417		11,940	
			269,158		130,129
Net assets			275,115		132,361
Funds of the charity					
Restricted funds			61,884		35,653
Unrestricted funds			213,231		96,708
Total charity funds	21		275,115		132,361

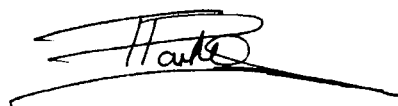
For the year ending 31 March 2021 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

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

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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

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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>

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

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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>

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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

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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

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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	213,231	61,884	275,115

	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	96,708	35,653	132,361

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)