

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

# **Alström Syndrome UK**

**Company Limited by Guarantee**

**Financial Statements**

**Year ended 31 March 2022**

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# Alström Syndrome UK

## Company Limited by Guarantee

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

#### Year ended 31 March 2022

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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**

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#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing Document**

The organisation is a charitable company, limited by guarantee, incorporated on 1<sup>st</sup> May 1998 and registered as a charity in the UK on 25<sup>th</sup> 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

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#### 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**

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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

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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

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##### 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

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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.

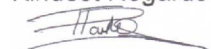
We began succession planning for the Board and for changes in staffing. I'm pleased to say this culminated in a smooth handover to our new Chief Executive Kerry as Ann became our new Executive Director with responsibility for our Global work. In addition, I began a handover to one of our Trustees Sharon 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 9<sup>th</sup> 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

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#### 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**

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#### **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

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#### 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 23<sup>rd</sup> 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

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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

28<sup>th</sup> November 2022

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# Alström Syndrome UK

Company Limited by Guarantee

## Statement of Financial Activities (including income and expenditure account)

Year ended 31 March 2022

		Unrestricted funds £	2022 Restricted funds £	Total funds £	2021 Total funds £
	Note				
<b>Income and endowments</b>					
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
<b>Total income</b>		<u>190,599</u>	<u>109,425</u>	<u>300,024</u>	<u>375,024</u>
<b>Expenditure</b>					
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
<b>Total expenditure</b>		<u>153,815</u>	<u>149,378</u>	<u>303,193</u>	<u>232,270</u>
<b>Net (expenditure)/income</b>		<u>36,784</u>	<u>(39,953)</u>	<u>(3,169)</u>	<u>142,754</u>
Transfers between funds		1,955	(1,955)	–	–
<b>Net movement in funds</b>		<u>38,739</u>	<u>(41,908)</u>	<u>(3,169)</u>	<u>142,754</u>
<b>Reconciliation of funds</b>					
Total funds brought forward		213,231	61,884	275,115	132,361
<b>Total funds carried forward</b>		<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 £	£
<b>Fixed assets</b>					
Tangible fixed assets	16		6,032		5,957
<b>Current assets</b>					
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	
<b>Creditors: amounts falling due within one year</b>	19	132,338		8,417	
			265,914		269,158
<b>Net assets</b>			271,946		275,115
<b>Funds of the charity</b>					
Restricted funds			19,976		61,884
Unrestricted funds			251,970		213,231
<b>Total charity funds</b>	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 23<sup>rd</sup> 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**

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#### **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

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#### 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**

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#### **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 £
<b>Donations</b>			
General donations	<u>1,449</u>	<u>–</u>	<u>1,449</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
<b>Donations</b>			
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	<u>19,137</u>	<u>–</u>	<u>19,137</u>
	<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	<u>6,119</u>	<u>–</u>	<u>6,119</u>
	<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

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

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# Alström Syndrome UK

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 March 2022

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#### 17. Debtors

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

#### 18. Investments

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

#### 19. Creditors: amounts falling due within one year

	<b>2022</b>	2021
	<b>£</b>	<b>£</b>
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

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#### 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)
<b>Net assets</b>	<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)
<b>Net assets</b>	<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)