



Alström Syndrome UK



**Raising Awareness, Advancing
Diagnosis, Improving the Care,
Treatment and Support for people
living with Alström Syndrome in the UK**

Annual Report and Financial Summary 2015/16

Registered Charity no: 1071196

Registered Company no: 3557191

With Your Help, We Have Hope

The Trustees, who are also Directors for the purposes of company law, present their report and the unaudited financial statements of the company for the year ended 31 March 2016.

A Word from Our Chair, Michelle Hough

It is with great pleasure that I introduce our annual report and accounts.

First and foremost I would like to thank our fantastic supporters and funders, without your support our vital work would not be possible.

It has been another very busy year, full of highlights and even in the current economic climate we have been able to generate funds to maintain our support and vital work.

We have continued to develop the support we offer to families, including more specific support around transition to help young people have their voice heard.

One of my passions is to develop further research initiatives to learn more into this complex condition, and in 2016 we have many exciting research projects starting. These include our first clinical trial into AS and we will also be starting a 'Lifestyle Audit' which will enable us to support healthy lifestyle choices with the aim of improving quality and longevity of life.

In May 2016, I will be delighted to attend the Alström Syndrome International conference in the USA. I am looking forward to meeting families from across the world with this ultra rare condition and learning from each others experiences. This will hopefully aid our work and collaboration with professionals internationally to seek the best treatments for our families and develop research initiatives together.

ASUK will also be moving into a new and exciting phase as we will be saying goodbye to Interim Chief Executive Officer, Martin Henwood and recruiting a new CEO. Martins work has centred around the strategic development of ASUK and in early 2016 we will be appointing a permanent Chief Executive Officer to develop the charity further and ensure we are sustainable into the future.

On behalf of our Trustees, I would also like to take this opportunity to thank our dedicated support team, who continue to support families and make a positive difference to the lives of families affected by this ultra rare condition.



Michelle

Michelle Hough, Chair

With Your Help, We Have Hope

Our work and What is Alström Syndrome?

Alström Syndrome is an ultra rare genetic disorder which causes progressive blindness and deafness and can also lead to heart and kidney failure, diabetes, liver dysfunction and associated problems. These manifest at different times often making diagnosis very difficult, leaving the patient without the specialist help that they need.

Since being founded in 1998, Alström Syndrome UK (ASUK) has grown from strength to strength. We now offer tailored support and services to families and individuals affected by the condition, and work alongside professionals in this specialist field to lead the way in research and finding better treatments for patients.

The Charities activities for the public benefit

The charity is governed by the charities' memorandum and articles of association, Trustees have referred to the general guidance on public benefit when reviewing the charities objectives which are as follows:

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

Corporate Governance improvements

During 2015/16 the Board of Trustees strengthened the corporate governance of the charity. In particular, there was a focus on ensuring the sustainability of the charity and focusing on key priorities such as family support and communication.

At the beginning of 2015 the Board confirmed that the core function of the charity remained to **Focus on our patients, families and carers.**

To deliver this our Priorities were identified as:

1. Reinforce the NHS contract
2. Raise awareness and collaborate with other organisations
3. Review and enhance our research programme
4. Have fun in raising funds
5. Create and develop our team
6. Develop our communications
7. Improve our corporate governance

These priorities provide the platform for further work to develop the charity on a sustainable basis in the short and medium term, as far as is possible when the key core contract is with NHS England during a period of extended austerity.

With Your Help, We Have Hope Our Achievements

In 2006, ASUK established the world's first Alström Syndrome specialised multi-disciplinary clinics, where patients can get the specialist medical advice and treatment they need all in one place. These clinics are held at Birmingham Children's Hospital and the Queen Elizabeth Hospital, Birmingham, UK.

Quoting one young person: **'It was a great relief to be seen by all the Doctors in one place who had expertise in Alström Syndrome and to meet other people with the same condition for the first time in my life'**

ASUK continue to support 70 families in the UK. We continually look at ways to raise awareness as we think this number could be higher due to the difficulties in diagnosis.

We were delighted in 2013 to accept the EURORDIS Award in recognition of extraordinary work and commitment to patient support and advocacy for people affected by Alström Syndrome. This raised our profile in Europe and globally, and created opportunities to collaborate with other professionals who endeavour to make a difference to the lives of people affected by Alström Syndrome.

During 2015 and 2016, ASUK offered these services and support:

Clinics: Specialised Medical Screening Clinics

Support: Provided a Help Line for Families and Professionals

Produced and Distributed a Medical Handbook

Dedicated National Family Support offering advice on benefits, school, college and career options, transition, health and fitness information, independent living options, accessing local services and activities

Organised a Family and Professional Conference

Continued to provide an Equipment Fund and Family Bike Club

Organised Family Activities and Fun-Filled Trips

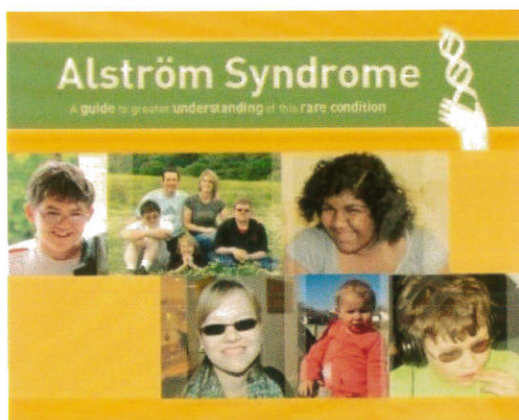
Alström Syndrome Training for Health and Education Professionals

An Informative Website for Families and Professionals

Research: Pioneering Research

A Clinical Patient Database

A Primary Cell and Tissue Bank



Our Medical Handbook

'A guide to greater understanding of this rare condition' can be obtained from our registered office.

With Your Help, We Have Hope

Our Achievements continued

Alström Clinic Development

The multi-disciplinary clinics are now very well established and through our contract with NHS England, we continue to deliver on our service specification within our role as partners in the service. We work closely with the teams at Birmingham Children's Hospital (BCH) and the Queen Elizabeth Hospital (QEH) and the feedback we have all received from those attending these clinics has been excellent. New tests have been introduced to the adult service and Cardiac MRI's, CT Angiograms and Fibroscans are now regular tests conducted within the general clinic. Any additional tests required within the children's clinics are also arranged when required. We also provide a help line, coordinate clinics for families, produce a newsletter and update our dedicated website.

This year we say farewell to the following people:

Lesley Porter, Clinic Coordinator, BCH
Hazel Riggall, Dietitian, BCH
Robin Paijmans, Clinical Psychologist, QEH

ASUK would like to thank them for their hard work over the years and wish them all the best for the future.

We now have four new members who have joined the clinical teams:

Lindsay Wilson, Clinic Coordinator, BCH
John Pemberton, Dietitian, BCH
Dr Shanat Baig, Clinical Research Fellow, QEH
Vishy Veeranna, Research Charge Nurse, QEH

We are delighted to have them on board and a new Psychologist will be added to the QEH team during the summer of 2016.

Research Development

We are now embarking on the first clinical trial for people diagnosed with AS in the UK. QEH opened as the trial centre for the AS study in December 2015 and the first patient was recruited in February 2016. We will provide updates on the outcome of the trial as soon as we are able to. We are providing support to families and individuals throughout the trial and we are working closely with the research team at QEH.

Our National Development Manager, Kerry Leeson-Beevers (*pictured below*) has continued to attend and present at numerous conferences and events throughout the UK and Europe this year to raise awareness of AS and the work of ASUK. Kerry continues to be an active member of the Patient Engagement Group who monitor the implementation of the UK Strategy for Rare Diseases and she continues to have an active role with EURORDIS on the Paediatric Committee at the European Medicines Agency.

Kerry gives her thoughts;
"This is a very interesting time for rare diseases, genetics and drug development. We will continue to work in collaboration with organisations who have similar interests to campaign for the rights of people affected by rare diseases and to work together to ensure everyone receives good quality health, education, social care and support."



With Your Help, We Have Hope

A Word from Our National Development Manager, Kerry Leeson-Beevers

Kerry Leeson-Beevers (*pictured bottom left*) gives her thoughts about ASUK's journey this year and future developments:

"It has been another excellent year for ASUK, full of new and exciting developments. I continue to thoroughly enjoy my role within the charity and feel proud of our achievements this year. We are continually looking at ways we can develop the service we offer to families and individuals and we monitor the NHS clinical service to ensure it is meeting the needs of people affected by Alström Syndrome (AS).



Following the success of our Asian Mentoring Scheme, the Sylvia Adams Charitable Trust would like to continue working with us to develop this work further. We submitted a project proposal and we have managed to secure £150,000 for a new project called Breaking down Barriers. The project is aimed at facilitating 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 who are at increased risk of having children with a genetic condition but who are unlikely or unable to access mainstream services. I am supported by an Advisory Panel who have a wealth of knowledge and experience in the field of genetics and I am so pleased to be given the opportunity to develop a project that we believe will be extremely beneficial and hopefully a great success. Breaking down Barriers is a three year project and it was launched in January 2016. On behalf of ASUK I would like to thank The Sylvia Adams Charitable Trust for their continued support and for their passion and enthusiasm in wanting to make a difference to the lives of people affected by genetic conditions.

Family support will always remain the priority for ASUK. Alongside this personalised support, we have also provided family activities such as the sailing trip (*pictured right*). We will be able to expand upon this work in 2016 following our successful Children in Need grant application. This funding will help develop our work around transition and we are pleased to welcome Marie McGee as National Transition Coordinator to our team. Marie is also part of the BCH service so having her work across both the hospital and the charity has proved very beneficial and enabled the young people to produce some useful resources.



The majority of my time is now taken up managing these new projects but I will always find the time to support our members. I still carry out the occasional home or school visit and I am always available if anyone wants to speak to me. I continue to deliver AS training to schools and colleges and regularly write reports to support members when required.

In consultation with our members, we are planning a re-brand for 2016 where we hope to give the charity a new fresh look. Catherine works extremely hard in the charity office to maintain our website and share our news via email and social media and I have every confidence that she will have everything looking fantastic in no time.

Thank you to all of our families for their continued support and to our funders who provide us with the financial resources to enable us to carry out our work."

With Your Help, We Have Hope

A Word from Our Family Support Officer, Iram

"I have enjoyed my role within the team by giving emotional and practical support to families that continue to have long or short term difficulties. I believe working closely with professionals and supporting families through a range of issues has led to an increase in patient confidence and empowerment.

It has always been my passion to meet people from different cultures, backgrounds and faiths, this has been achieved by attending many events around the country including focus group meetings, Actionnaire workshops, MySense events and Kidz in the middle exhibitions.

Attending these events has increased my capacity and knowledge to widen the support I give to our families.

I was honoured to be part of the Genomic Medicine programme this year as a speaker to present 'My Life My Journey' to professionals, postgraduates and doctorates. This is a huge achievement for me as it has given me the confidence to present at a high level. I really enjoyed my time networking with professionals and further raised the profile of ASUK.

I have attended many workshops this year alongside patient group meetings, Education, Health and Care plan review meetings and thoroughly enjoy working with professionals from all health, social and educational settings. Family support will always be the heart of what I do and I look forward to serving our families and young people in the future"

Iram will be leaving soon to have her baby but we would like to take this opportunity to offer reassurance that we will ensure the support offered to families continues and we will be advertising for Family Support Workers to cover the whole of the UK. We thank Iram for the support she has given to families and we wish her and her family all the best.



Getting to Know You Residential

In March 2016, families took part in the 'Getting to Know You' weekend at Whitemore Lakes, Staffordshire funded by Children in Need. The purpose of the weekend was for families to get to know each other, try out new activities and above all have fun! Abseiling, Zip Wiring, Archery, Problem Solving, Art and High Ropes were just some of the activities that families enjoyed. Although the weather was a little cold, every one threw themselves into the activities which also included a campfire with popcorn, toasted marshmallows, singing silly songs and lots of fun! Parents and carers also enjoyed 'Dads Yoga' and jewellery making. The games proved to be very popular, with the adults enjoying them so much that they had to extend the session for an extra hour!

The Children in Need funding has helped create opportunities and activities which families can enjoy. ASUK will continue to consult, organise and offer some unique activities for all to enjoy. The Transition project is now in its second year. We are planning activities throughout 2016 to include specialised driving lessons, bowling, visit to University Hospital Birmingham to prepare young people for their eventual transfer to adult care and a water sports weekend.



With Your Help, We Have Hope

A Word from Our National Transition Coordinator, Marie McGee

My role as National Transition Co-ordinator, evolved from funding provided by Children in Need. I work with the children and young people aged between 11-18 years old and their families to support them across many aspects of their lives which includes, managing Education, Health and Care plans, accessing social care, developing resources and providing opportunities to take part in activities both locally and nationally. Since the start of the project I have organised 'Foodie, Fun Friends Clubs'. This is a pre clinic workshop which concentrates on food preparation, creation and of course tasting! One young person commented 'I loved the workshop, making the food is great fun!' The workshops are supported by John Pemberton, Dietitian from BCH with the emphasis being on healthy living, portion size and food combinations. Fun and interaction are at the heart of the workshops with lots of opportunities to get to know one another and make friends.

Hear My Voice Forum

In September 2015, eleven young people came together to create the Hear My Voice Youth Forum (HMYV). One of the first projects HMYV produced was the creation and launch of transition resources aimed at developing an understanding of transition in healthcare, and the knowledge and skills required to navigate this time period in a young person's life. Members of the HMYV Forum (*pictured right*) have also taken part in interview panels to recruit new ASUK team members.



T- KASH Knowledge and Skills in Healthcare

Young people who attend the AS multi-disciplinary Clinics at Birmingham Children's Hospital had highlighted gaps in their knowledge and skills to manage their healthcare. Over a 10 month consultation period the young people created a range of posters and symbols which:

- Draw attention to the knowledge and skills young people should be developing to manage their healthcare, while having the best life possible
- Prepare young people and families for identifying and coping with change at key points in their lives
- Supporting young people to plan for their future



The resources were launched in February at the British Paediatric Surveillance Unit (BPSU) during the Rare Disease Day Conference 2016. The resources can be used by any clinical speciality and are free to any health, education or charity group to inform their staff and families about what young people want to say. The impact this project has had is amazing. Our young people have created some brilliant transition resources. All the young people worked so hard and together they can see the difference that can be achieved!

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A Word from Our Office Manager, Catherine Lewis, Events and Fundraising

We organised a successful Family and Professional Information and Activity day in September at New College Worcester. The event brought together families and professionals to learn more about the clinical and research developments alongside informative workshops and lots of fun activities. This was a more informal style conference to give families the chance to come together in a relaxed environment to get to know one another, share experiences and most importantly have some fun!

ASUK Family and Professional Information and Activity Day 2015



Fundraising

Despite a continually challenging financial environment Alström Syndrome UK has continued to generate funds through grant making trusts, family fundraising and grant applications. A **HUGE THANK YOU** to everyone who continues to support our great cause, the funds raised really do make a huge difference to families living with this ultra rare condition. Through this support we have been able to provide activity holidays to provide lasting memories for families, a hardship fund and a 'Raise a Million' fund to enable research development.

Children in Need Transition Project

We were delighted to receive funding from Children in Need in May 2015 to ensure young people of transition age receive the dedicated support needed. The project will work with young people affected by Alström Syndrome and their siblings and parents. We will provide fun activities and one to one support to ensure that young people who are affected are less isolated, healthier and able to better manage change. We will also be providing regional support groups and activities for everyone to get involved in.



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ASUK Bike Club

The ASUK Bike Club continues to be a great success, following successful funding from Sport England. This year we were able to provide a further 8 tandems for families to enable them to exercise in a safe and fun way. Exercise is vitally important in the overall management of AS, as obesity is common which can often lead to type 2 diabetes. One of our families gives their thoughts;

"A huge thank you for ordering our tandem. Wow it is the first time we have all been able to get out and cycle together, exercise can be fun!"



YOU MAKE A DIFFERENCE

Our families and supporters continue to raise funds for our great cause and a special mention to our brave Virgin London Marathon runners Brian Vasey and David Lunt (*pictured right*), 2015 was his 21st Marathon!

Due to the kind support of our sponsors New College Worcester, Retro Box Gifts, HearFirst Training, RKD Films and Custard Moon entertainments we continue to produce a family calendar which raises vital funds each year and showcases the inspirational families we work with. Thank you also to Williams Holidays who have chosen ASUK to be their charity of the year, raising vital awareness and funds through 'Coach Seats for Great Causes'.



Great News, following the success of our Asian Mentoring Scheme (AMS) project in 2011, the Sylvia Adams Charitable Trust who contributed funding towards this project would like to bring organisations together to develop this work further. This will be focused on sharing good practice and developing new guidelines to highlight effective ways to support families who are at increased risk of having children with a genetic condition but who are unlikely or unable to access mainstream services.

This new and important project is called '**Breaking down Barriers**'

Charitable trusts and grant giving bodies have our deepest gratitude. The ability of Alström Syndrome UK to achieve its objectives as a charity is dependent on the generosity of many charitable trusts and grant giving bodies.

Grants received during the year:

Albert Hunt Trust	£1,000
Children in Need	£23,690
Dandia Charitable Trust	£2,000
Hafele Charity Fundraising Committee	£25
Hamilton Wallace trust	£500
Keith Coombes Foundation	£500
KET Charitable Trust	£400
Lynn Foundation	£500
The Michael and Anna Wix Charitable Trust	£200
Millichope Foundation	£2,000
The Roger Vere Foundation	£200
Reuben Foundation	£250
Shaw Meades Charitable Trust	£650
Sir John Sumner's Trust	£250
The Steven Bloch Image of Disability Charitable Trust	£200
Sylvia Adams Charitable Trust	£20,000
Sylvia Aitken Charitable Trust	£1,500
Sylvia and Colin Shepherd Trust	£800
Ulverscroft Foundation	£2,200
Wessex Water	£150

Our heartfelt thanks go to everyone who has supported ASUK throughout the year, without this support our work would not be possible.

With Your Help, We Have Hope

Governance, Trustees

The Board of Trustees evolved during what was a demanding year. The appointment of Dr Richard Paisey has already proved helpful in supporting the re-draft of our medical handbook and supporting our research developments.

Vice Chair, Trevor Parkin monitors our finances and Finance Manager, Steve Scofield produces detailed budgets prior to each Trustee meeting so we can ensure future sustainability.

New Trustees are appointed by the existing Trustees and serve for three years after which they may put themselves forward for re-appointment. A minimum of three Trustees must be present at each meeting for decisions to be made. Trustees meet together on a regular basis which includes both face to face meetings as well as telephone meetings.

Trustees all undergo relevant training including, child protection training before joining the Board. New Trustees are given a copy of the memorandum and articles of association and copies of the Charity Commission guidance "The Essential Trustee: What you need to know".

Trustees give of their time freely and are required to disclose all relevant interests, in accordance with the charities policy and withdraw from decisions where a conflict of interest arises or could be perceived to arise.

Management of Risk

The Trustees have reviewed the major risks to which the charity is exposed, and systems or procedures have been established to manage those risks.

The Trustees have identified that the main opportunity and risk for the Charity is:

- The NHS England clinic contract

Reserves Policy and Going Concern

The Trustees review the level of reserves on a regular basis to ensure that the appropriate levels are maintained in light of the main risks to the organisation and future developments. The charity seeks to maintain liquid unrestricted funds at the level of twelve months planned expenditure, which provides sufficient funds to cover unexpected costs and other expenditure, which arise from time to time. At the year-end there was 28.68 (2015 11.45) months of expenditure in cash and free reserves. 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.

Investment Policy

Under the Memorandum and Articles of Association the charity has power to make any investment which the Trustees think fit. The Trustees make and hold investments using the general funds of the charity. The determining factor will be the sustainability of the charity, and placement of the funds with a view to security, liquidity, and return.

Plans for the Future

The Trustees will be appointing a new permanent Chief Executive Officer in 2016 to aid the future sustainability of the charity. The main priority of the charity; family support will be strengthened through the recruitment of additional support workers to ensure that no matter where families live they will receive the same personalised support. We will endeavour to forge ahead with research projects, which we hope will lead to a better understanding of this rare condition and work collaboratively with other organisations on an International level, so that we can collectively improve the lives of people with complex rare conditions. The Trustees are proud of all of our achievements and we strive for these to continue into 2016/17.

With Your Help, We Have Hope

Governance continued

Trustees' Responsibilities for the Financial Statements

The Trustees are responsible for preparing the Annual Report and the financial statements in accordance with applicable law and regulations.

Company law requires the Trustees to prepare financial statements for each financial year.

Under that law the Trustees have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). The financial statements are required by law to give a true and fair view of the state of affairs of the group and the company and of the net incoming or outgoing resources for that period. In preparing those financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

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

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

Small company provisions

This report has been prepared in accordance with the special provisions for small companies under section 415A of the Companies Act 2006.

Independent Examiner

Stephen Cresswell BA FCA DChA has been re-appointed as independent examiner for the ensuing year

On behalf of the Board


.....
Michelle Hough
Director
5 November 2016

With Your Help, We Have Hope Further Information

Trustees

The trustees who served the company during the period were as follows:

Michelle Hough (Chair)
Trevor Parkin (Vice Chair)
Alexandra Griffiths Rayson
Julie Beck
Dawn Mayes
Kez Hayat
Dr Richard Paisey

Registered Office Address:

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Registered Company no: 3557191

Bankers

Lloyds Bank
2 Palace Avenue
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TQ3 3ER

Independent Examiners

Stephen Cresswell BA FCA DChA
Thomas Westcott Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ



Alström Syndrome UK

Financial Statements for the Year Ended 31st March 2016

Statement of Financial Activities

	Note	Unrestricted Funds	Restricted Funds	Total 2016	Total 2015
		£	£	£	£
Income and endowments					
Donations and legacies	2	7,461	1,483	8,944	27,611
Investment Income	3	1,680	0	1,680	1,698
From other activities	4	8,000	184,797	192,797	163,105
Total		17,141	186,280	203,421	192,414
Expenditure					
Raising Funds	5	216	0	216	337
Charitable Activities	6	14,800	152,196	166,996	186,427
Total		15,016	152,196	167,212	186,764
Net Incoming/(Expenditure) for the Year		2,125	34,084	36,209	5,650
Net Movement in Funds		2,125	34,084	36,209	5,650
Total Funds Brought Forward		76,771	94,401	171,172	165,522
Total Funds Carried Forward		78,896	128,485	207,381	171,172

Alström Syndrome UK

Financial Statements for the Year Ended 31st March 2016

Balance Sheet

	Note	2016 £	2015 £
Current Assets			
Debtors	9	1,844	131
Investments	10	14,965	99,965
Cash at Bank & in hand		212,556	78,284
Total Current Assets		229,365	178,380
Liabilities			
Creditors - amounts falling due within 1 year	11	21,994	7,208
Net Assets		207,381	171,172
Analysed by;			
Unrestricted Funds	13	78,896	76,771
Restricted Funds	14	128,485	94,401
Total Charity Funds		207,381	171,172

For the year ended 31 March 2016 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Trustees' responsibilities:

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

These financial statements were approved by the members and authorised for issue on 5 November 2016 and are signed on their behalf by:


Michelle Hough

Chair

Company number 3557191

Alström Syndrome UK
Financial Statements for the Year Ended 31st March 2016
Notes to the Accounts

1 Accounting Policies

The principal accounting policies are summarised below. These policies have been applied consistently throughout the year.

(a.) Basis of Accounting.

The financial statements have been prepared under the historical cost convention. The financial statements have been prepared in accordance with FRS102, the Charities SORP (FRS102) and the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Charities SORP (FRS102). The charity transitioned to FRS102 as of 1 April 2014, there have been no transitional changes required. The financial statements are prepared in sterling which is the functional currency of the charity.

(b.) Fund Accounting.

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity.

Restricted Funds are subjected to restriction on their expenditure by the donor.

(c.) Incoming Resources.

All incoming resources are included in the statement of financial activities when the charity is entitled to, and virtually certain to receive, the income and the amount can be quantified with reasonable accuracy.

Donations and legacies received are included in the full Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the Charity, are recognised when the Charity becomes unconditionally entitled.

Investment Income is included when it is earned.

Incoming resources from grants, where related to performance and specific deliverables are accounted for as the Charity earns the right to consideration by its performance.

(d.) Resources Expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates.

Costs of generating funds comprise the costs associated with attracting voluntary income and the cost of investing and trading for fundraising purposes.

Charitable expenditure comprises those costs incurred by the Charity in the delivery of its activities and costs of an indirect nature necessary to support them.

The nature of the Charity is such that all costs are allocated directly to the expenditure categories of the SoFA without need for apportionment.

(e.) Fixed Assets

The nature of the Charity is such that it has no fixed assets.

Notes to the Accounts
2 Donations and legacies

	Unrestricted funds £	Restricted funds £	2016 Total £	Unrestricted funds £	Restricted funds £	2015 Total £
General Donations	7,461	1,483	8,944	27,611	0	27,611

3 Investment income

	Unrestricted funds £	Restricted funds £	2016 Total £	Unrestricted funds £	Restricted funds £	2015 Total £
Bank interest receivable	1,680	0	1,680	1,698	0	1,698

4 From other activities

	Unrestricted funds £	Restricted funds £	2016 Total £	Unrestricted funds £	Restricted funds £	2015 Total £
<u>Grants received</u>						
Unrestricted	8,000	0	8,000	0	0	0
National Commissioning Grant	0	138,657	138,657	0	136,945	136,945
EU-WABB	0	0	0	0	8,929	8,929
Transition Activities	0	23,690	23,690	0	1,500	1,500
Asian Mentoring Scheme	0	20,000	20,000	0	0	0
Family Support	0	2,450	2,450	0	14,692	14,692
Research and Development	0	0	0	0	1,039	1,039
	8,000	184,797	192,797	0	163,105	163,105

5 Raising Funds

	Unrestricted funds £	Restricted funds £	2016 Total £	Unrestricted funds £	Restricted funds £	2015 Total £
Administration costs	216	0	216	337	0	337
	216	0	216	337	0	337

6 Cost of Charitable Activities- by activity

	Unrestricted funds £	Restricted funds £	2016 Total £	Unrestricted funds £	Restricted funds £	2015 Total £
National Commissioning Grant	0	130,459	130,459	0	136,945	136,945
EU-WABB	0	0	0	0	8,929	8,929
Transition Activities	0	18,236	18,236	0	0	0
Asian Mentoring Scheme	0	0	0	0	13,074	13,074
Family Support	0	3,501	3,501	0	9,217	9,217
Research and Development	0	0	0	0	0	0
Support costs	14,800	0	14,800	8,415	0	8,415
	14,800	152,196	166,996	8,415	168,165	176,580

7 Net incoming resources for the year

	2016 £	2015 £
Net incoming resources is stated after charging: Independent examiners' fee	1,400	1,200

Alström Syndrome UK

Financial Statements for the Year Ended 31st March 2016

Notes to the Accounts

8 Taxation

The charity's activities fall within the exemptions afforded by the provisions of the Income and Corporation Taxes Act 1988. Accordingly, there is no taxation charge in these accounts.

9 Debtors

	2016 £	2015 £
Prepayments & Accrued Income	1,844	131

10 Investments

	2016 £	2015 £
Cater Allen Deposit	0	85,000
Virgin Deposit	14,965	14,965
	<u>14,965</u>	<u>99,965</u>

11 Creditors: amounts falling due within one year

	2016 £	2015 £
Accruals	21,994	7,208

12 Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	Total funds £
Fund balances at 31 March 2016 as represented by			
Current assets	81,870	147,505	229,375
Current liabilities	(2,974)	(19,020)	(21,994)
	<u>78,896</u>	<u>128,485</u>	<u>207,381</u>

Alström Syndrome UK

Financial Statements for the Year Ended 31st March 2016

Notes to the Accounts

13 Unrestricted funds

	At 1 April 2015 £	Incoming Resources £	Outgoing Resources £	At 31 March 2016 £
General fund	75,636	17,141	15,016	77,761
Financial Assistance Grant Fund	1,135	0	0	1,135
	<u>76,771</u>	<u>17,141</u>	<u>15,016</u>	<u>78,896</u>

Purposes of unrestricted funds

General fund

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

Financial Assistance Grant Fund

Amount set aside to provide financial support for patients and their families who are affected by Alström Syndrome based upon an assessment of need.

14 Restricted funds

	At 1 April 2015 £	Incoming Resources £	Outgoing Resources £	At 31 March 2016 £
National Commissioning Grant	0	138,657	130,459	8,198
<u>Transition Activities</u>				
Allergan Foundation	16,200	0	0	16,200
St James's Place Foundation	10,000	0	7,787	2,213
Children in Need	0	23,690	10,449	13,241
Smaller restricted funds	3,532	0	0	3,532
<u>Sylvia Adams Charitable Trust</u>				
Asian Mentoring Scheme	11,454	0	0	11,454
Breaking down Barriers	0	20,000	0	20,000
<u>Family Support</u>				
Awards for All	8,992	0	403	8,589
Bradford and District CNET	2,013	0	0	2,013
Chloe Staddon Holiday & Equipment Fund	2,454	0	0	2,454
Genetic Disorder	3,144	0	0	3,144
Jeans for Genes	5,000	0	0	5,000
Sport England	2,329	0	0	2,329
Ulverscroft Foundation	0	2,200	0	2,200
Smaller restricted funds	9,077	1,233	3,098	7,212
<u>Research and Development</u>				
One in a million	17,755	500	0	18,255
Smaller restricted funds	<u>2,451</u>	<u>0</u>	<u>0</u>	<u>2,451</u>
	<u>94,401</u>	<u>186,280</u>	<u>152,196</u>	<u>128,485</u>

Alström Syndrome UK

Financial Statements for the Year Ended 31st March 2016

Notes to the Accounts

14 Restricted funds continued

Purposes of restricted funds

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 patients and their families who are affected by Alström Syndrome .

Allergan Foundation

Funding towards a Transitions Coordinator

St James's Place Foundation

Funding towards a Transitions Coordinator

Children in Need

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

Sylvia Adams Charitable Trust

Funding towards the Asian Mentoring Scheme which works specifically within Asian communities to offer support and raise awareness.

Funding Breaking down Barriers 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.

Awards for All

Funding toward a volunteering project.

Bradford and District CNET

Funding toward activity breaks

Chloe Staddon Holiday & Equipment Fund

Amounts raised to provide holidays, outings and specific equipment for patients and their families who are affected by Alström Syndrome.

Genetic Disorder

Amounts raised to provide holidays, outings and specific equipment for patients and their families affected by Alström Syndrome.

Jeans for Genes

Funding to produce an information DVD on living with Alström Syndrome.

Sport England

Funding to enable the purchase of tandems and specially adapted trikes.

Ulverscroft Foundation

Funding to produce a medical handbook and news letters.

One in a Million Fund

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

Smaller restricted funds

Restricted grants and donations of less than £2,000

15 Transactions with Trustees

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, 3 (2015 5)Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustee meetings these claims totalled £1,475 (2015 £2,927)

16 Company Limited By Guarantee

Alström Syndrome UK is a Company limited by guarantee and accordingly does not have a share capital. In the event of the company being wound up, the liability of each member is limited to £10.

I report on the accounts of the company for the year ended 31 March 2016, which are set out on pages 14 to 21.

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- Examine the accounts under section 145 of the 2011 Act;
- To follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act and;
- To state whether particular matters have come to my attention.

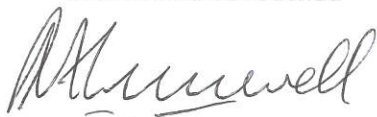
Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements:
- To keep accounting records in accordance with the section 386 of the Companies Act 2006 and
 - To prepare accounts which accord with the accounting records, comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice. Accounting and Reporting by Charities
- have not been met or
- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached



Stephen Cresswell BA FCA DChA

Independent Examiner

Thomas Westcott

96 High Street

Ilfracombe

EX34 9JH

5 November 2016