



Alström Syndrome UK



**Award Winning Charity Advancing
Diagnosis, Care, Treatment and
Providing Support for those living
with Alström Syndrome in the UK**

Annual Report and Financial Summary 2014/15

Registered Charity no: 1071196

Registered Company no: 3557191

With Your Help, We Have Hope

A Word from Our Chair

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 many exciting projects coming up in 2015, including pioneering research initiatives, essential transition support for young people and an exciting family activity and information day to look forward to.



One of my passions is to develop research initiatives to learn more about Alström Syndrome so that families have the treatments they need to manage the condition more effectively. We collaborate with professionals globally to seek the best treatments for our families and develop research initiatives together. The 'Raise a Million' fund was set-up specifically to raise funds for research projects and the cute and cuddly Giant Bolster (*pictured right*) was developed by my Daughter Millie and I to continue to raise funds and awareness.



Our approach with Trustees taking the Executive role in August 2013 was evaluated and updated in November 2014. We took that opportunity to invest in improving our financial accountability and governance systems.

Towards the end of the financial year we bade farewell to Kay Parkinson, our lead contractor and she is now Chief Executive of the Cambridge Rare Diseases Network. We look forward to working with her in the future and I would like to add my personal thanks to Kay for everything she did for ASUK, as founder and the award winning services she helped to create.

On behalf of our Trustees, I would also like to take this opportunity to thank our dedicated team of contractors, who continue to drive the charity forward 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. This reflects our Objects as a charity.

Objects of the Charity and activities for the public benefit

The objects of the charity are governed by the company's 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 2014/15 the Board of Trustees decided there was a need to strengthen the corporate governance of the charity. In particular, there was a focus on ensuring the sustainability of the charity following a significant deficit during 2013/14 was identified. To that end, it interviewed and appointed Martin Henwood as the Interim CEO (Chief Executive Officer) at the end of September 2014.

The following months saw the Board adopt a sustainable budget for 2015/16, and this was subsequently reinforced by a Strategy Day in February 2015 to which all Trustees and Contractors were invited. The Strategy Day led to the Board confirming that the core function of the charity remained as in our Objects i.e. **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 so patients can get all the specialist medical advice and treatment they need all in one place. In 2014/15 these clinics were held at Birmingham Children's Hospital and the Queen Elizabeth Hospital, Birmingham, UK.

Quoting one young lady **"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 continued to support 70 families in the UK. We sought to raise awareness as we feel this number could be much higher due to inaccurate diagnosis.

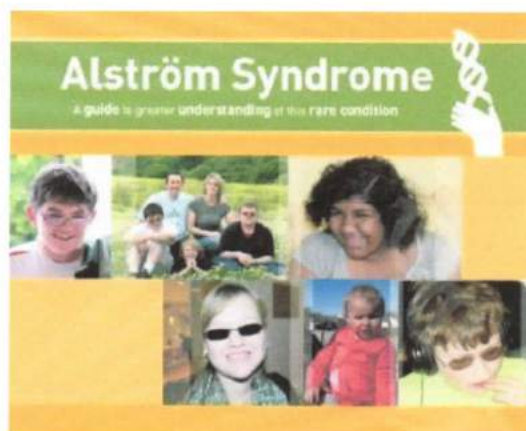
We were delighted in 2013 to accept the EURORDIS Award in recognition of extraordinary work and commitment to patient support and advocacy for people affected by Alström Syndrome. This raised our profile in Europe and globally, and created opportunities to collaborate with other professionals who endeavour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

During 2014/15, ASUK services offered and/or supported included:

Clinics: Specialised Medical Screening Clinics

Support: 24 Hour Help Line
Medical Handbook
Family and Professional Conference
Equipment Fund and Bike Club
Activity Projects and Fun-Filled Trips
Alström Syndrome Training
A Dedicated Website
Dedicated National Family Support

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

AlströmClinic Development

The multi-disciplinary clinics are funded by NHS England and still remain to be a vital part of our service and in March 2015, we conducted another successful audit of this clinical service and we were praised for the service which we provide. As part of this contract we also provide a 24 hour help line, coordinate clinics for families, produce a newsletter and update our dedicated website.

Support Development

In May 2014, we held a Transition clinic at the Queen Elizabeth Hospital which brought together young people of similar ages to offer the usual carousel of clinical tests alongside personalised workshops and fun activities to enable the family as a whole to be supported. Following this Transition clinic we applied for further funding from BBC Children in Need to fund further transition services for our young people. We are delighted that our application was successful and went live in spring 2015.

Research Development

LSE Project 'A cost-benefit analysis of multidisciplinary treatment and the impacts of eHealth Solutions'

With the assistance of our families and professionals involved, the London School of Economics published a report detailing the cost effectiveness of our AS clinics and the financial implications of having Alström Syndrome. The report concluded that the **'Benefits of the Clinics were found to be far reaching and great'** Patients commended the easy access to treatment, and the niche medical consultations, time saving due to fewer hospital visits, improved patient quality of life – both from a psychological viewpoint (more support available, less anxiety) and a socio-economic perspective (fewer work days lost, less travel between facilities). The report gave an insight into the impact that having such a rare condition has on our families, ways we can ensure we support more effectively and ensure families receive the best healthcare available.

Awareness Raising

We have continued the vital task of raising awareness to ensure we are reaching all parts of the UK and further afield to raise awareness. Too many of our families have waited unacceptable lengths of time to receive a diagnosis and with access to our medical teams, early diagnosis is crucial and enables us to ensure families are supported to manage the condition effectively. In our efforts to improve knowledge of AS we have delivered presentations and workshops at many high profile and prestigious events including:

- Medical Conferences
- RNIB / SENSE / Sight Village Events
- Acquired Deafblindness conference in Ireland
- World Orphan Drugs Congress in Brussels



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:

"I continue to enjoy my work within the charity and I am pleased that we are continuing our aim of being a patient led organisation. It is important to me that our families always remain our priority and that everything we do is in the best interests of the people we are here to support. My role has developed this year and while I continue to directly support families, I am also branching out into new areas to develop the charity, promoting research, raising our profile and involving ourselves in the wider issues affecting rare diseases.



- I have been elected as a patient representative on the Paediatric Committee at the European Medicines Agency
- I am a member of the Patient Engagement Group, tasked with overseeing the implementation of England's Rare Disease Strategy and a sounding board for Public Health England
- I am also a member of the Asterix Project – a European Project focusing on the issues around developing clinical trials for small populations

This year has seen many new important initiatives being introduced within the rare disease field. It is positive to see rare diseases high on the political agenda and people recognising the importance of understanding rare diseases and the relevance this will have on understanding more common conditions. This is evident with the implementation of the following projects:

- 100,000 Genomes Project
- UK Strategy for Rare Diseases
- National Congenital Anomalies and Rare Disease Registration Service
- NIHR Rare Disease Translational Research Collaboration

Looking to the future

We have exciting times ahead and I look forward to working with our families and contractors within ASUK to explore new avenues and potential areas for new research. We will also ensure we continue to provide high quality support to our families and fulfil our role within our NHS contract. Areas to look forward to and develop in the future:

- Provide more activity days for families
- Implement and develop the new Transition project
- Further Research collaborations to develop potential new drugs and treatments
- New Rare Disease Centre's at QEH and BCH
- Improve the sharing of information between BCH and QEH
- The development of European Reference Networks

I would like to thank our families for continuing to support our charity. I truly believe that by working together and sharing mutual respect, the collaborations we are forming are going to enhance our understanding of AS and in time bring new treatments to our families."

With Your Help, We Have Hope

A Word from Our Family Support Officer, Iram Shah

"I enjoy my role as Family Support Manager, I absolutely love working closely and supporting all families through a range of issues. I believe it's crucial to support our young people in education and I have found that empowering parents by attending annual review meetings alongside them has led to an increase in patient confidence and empowerment.



The support I give to families varies on a daily basis, whether it's chairing meetings at schools or supporting families through changes to the Education Health Care Plan (EHCP). Some common areas I offer support in are the application, renewal and appeals of benefits, housing issues, attendance of appointments/meetings to offer support, chairing of meetings such as the Common Assessment Framework (CAF), applications for small grants, signposting to support services, direct payment/ short break's support and much more.

I continue to advocate for families by supporting them through the AS multidisciplinary clinics.

The family home visits are an important part of early intervention as this I feel delivers, strengthens and builds on patient trust.

I have recently achieved a Post graduate Certificate in education to further my passion of supporting young people in education with Alström Syndrome.

I have attended numerous activities and events with families and love the social aspect of integrating with other families with similar conditions. Such events with Victa, Blind Children UK and Sight Village have been great successes, not only raising awareness but enabling families to come together.

I would like to thank our team and families who continue to support each other in order to fight the battle of Alström Syndrome.

I look forward to continuing to progress the charity forward and ensuring all families affected are supported."



With Your Help, We Have Hope A Word from Our Office Manager, Catherine Lewis, Our Family and Professional Events, and Fundraising

We organised another successful Family and Professional Conference in August 2014 in Torquay. The event brought together professionals from across Europe to discuss developments in research and provided useful information for families about money matters, benefits, technology and independent living advice. Whilst their parents attended the conference, the children had a fun-filled day at Crealy Adventure park. Many families stayed on in Torquay to enjoy the Torbay Family Activity Week, where fun was had by all.

Looking forward

In 2015, we have organised a very exciting event for both families and professionals in September at New College Worcester. This will be an informal conference which will provide information about our research developments and clinical updates alongside fun activities and useful workshops. The condition can be very isolating for families and this event will 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!

Fundraising

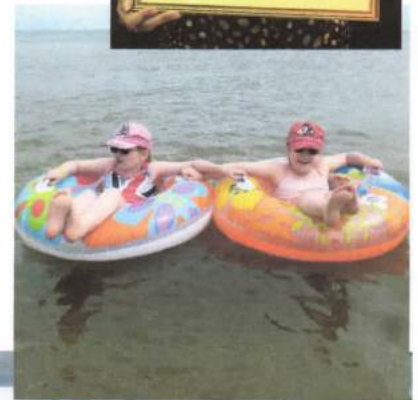
Despite a continually challenging financial environment Alström Syndrome UK has continued to generate funds through grant making trusts, family fundraising and grant applications. A **HUGE THANK YOU** to everyone who continues to support our great cause. The numbers of people being diagnosed with Alström Syndrome is increasing and 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.

The Sports Buddies Project

We were delighted to receive funding from Sport England in 2014/15 to develop a 'Sports Buddies' project and we used this to provide families with specially adapted trikes and tandems to enable them to exercise together in a safe and enjoyable way. Exercise is vitally important in the overall management of AS, as obesity is common despite attempts to monitor diet, which often leads to type 2 diabetes.

The project has enabled ASUK to develop a Bike Club where families can loan tandems/bikes from the charity and then pass onto another family when it is no longer needed. This ensures the longevity of this project and has enabled more families to be involved. 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, Lucy Leeson, Rik Bennett and David Lunt (*pictured right*), 2014 was his 20th Marathon!

Due to the kind support of our sponsors New College Worcester, Retro Box Gifts and HearFirst Training 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, we have been successful in our Children in Need funding application for a three year transition project. The project will work with young people affected by Alström Syndrome and their siblings and parents. By providing fun activities and one to one support with transition, ensuring 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. We would like to take this opportunity to thank BBC Children in Need, St James's Place, Allergan International Foundation, The Keith Coombes Foundation, The Hospital Saturday Fund, The Albert Hunt Trust, The Lynn Foundation and everyone else who contributed to our transition project and make a difference to lives of young people.



Supported by
BBC
**Children
in Need**

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Charitable trusts and grant giving bodies deserve 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:

EU WABB	£8,929	The Norman Family Trust	£500
Albert Hunt Trust	£1,000	The Really Useful Group Ltd	£500
Armourers & Brasiers Gauntlet Trust	£500	Reuben Foundation	£250
The Chapman Trust	£1,000	Shaw Meades Charitable Trust	£1,033
Dandia Charitable Trust	£1,500	The Shanly Foundation	£2,000
Douglas Arter Foundation	£1,000	Sir John Sumner's Trust	£1,000
The Foresters Charity Trust	£2,000	South West Water	£100
GOLR Cup of Kindness	£1,452	Sovereign Healthcare Trust	£1,000
Groveglade Trust	£2,000	Sport England	£9,740
The J & D Hambro Charitable Trust	£1,000	Sylvia Aitken Charitable Trust	£500
The James Wise Charitable Trust	£250	Sylvia and Colin Shepherd Trust	£800
Keith Coombes Foundation	£500	Ulverscroft Foundation	£1,000
KET Charitable Trust	£400	The Weinstein Foundation	£50
Lynn Foundation	£500	Wessex Water	£150
The Michael and Anna Wix Charitable Trust	£100	William & Christine Eynon Charity	£50
Millichope Foundation	£2,000		

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. Curtis Vasey and Mark Millais have both decided to step down from the Board. Curtis and Mark have both been dedicated Trustees and we would like to thank them sincerely for their commitment and support over the years. We are delighted to announce that Dr. Richard Paisey has joined the Board of Trustees. Richard has been part of ASUK's journey since it began, and his expertise and experience of this very rare condition will be a major boost for ASUK, especially in our future research work and related developments.

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.

One of the corporate governance improvements introduced during the year is a set timetable for Board meetings, with a requirement that at least three of these meetings will be in person. This maintains the benefits of added flexibility of some virtual Board meetings but ensures and enables team development of the Board to the benefit of the charity.

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.

The Annual Report and financial statements have been prepared in accordance with the requirements of the Statement of Recommended Practice on accounting and reporting for charities (revised 2005).

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

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 three 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 11.45 (2014 10.44) months of expenditure in cash and free reserves. The Trustees have reviewed the allocation of reserves in prior years and have combined certain smaller restricted funds with the same restrictions. The review highlighted £3,961 of unrestricted reserves which had been included in restricted reserves these have now been transferred to the correct fund.

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.

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.

On behalf of the Board


.....
Michelle Hough
Director


.....
Date

With Your Help, We Have Hope Further Information

Trustees

Michelle Hough (Chair)

Trevor Parkin (Vice Chair)

Alexandra Griffiths Rayson

Julie Beck

Dawn Mayes

Kez Hayat

Dr. Richard Paisey—appointed February 2015

Mark Millais—resigned August 2014

Curtis Vasey—resigned November 2014

Registered Office Address:

31 Shearwater Drive

Torquay

Devon

TQ2 7TL

Tel: 01709 210151 / 01803 613117

Email: info@alstrom.org.uk

Website: www.alstrom.org.uk

Registered Charity no: 1071196

Registered Company no: 3557191

Bankers

Lloyds TSB

2 Palace Avenue

Paignton

Devon

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 2015

Balance Sheet

	Note	2015 £	2014 £
Current Assets			
Debtors	9	131	3,911
Investments	10	99,965	114,965
Cash at Bank & in hand		78,284	47,646
Total Current Assets		178,380	166,522
Liabilities			
Creditors - amounts falling due within 1 year	11	7,208	1,000
Net Assets		171,172	165,522
Analysed by;			
Unrestricted Funds	13	76,771	62,100
Restricted Funds	14	94,401	103,422
		171,172	165,522

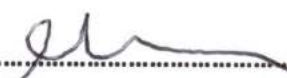
The Directors are satisfied that the company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477, and that no member or members have requested an audit pursuant to section 476 of the Act.

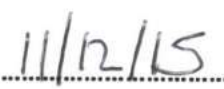
The Directors acknowledge their responsibilities for:

- (i) ensuring that the company keeps adequate accounting records which comply with section 386 of the Act, and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of the financial year and of its profit or loss for the financial year in accordance with the requirements of sections 394 and 395, and which otherwise comply with the requirements of the Act relating to financial statements, so far as is applicable to the company.

These financial statements have been prepared in accordance with the special provisions for small companies under section 415A of the Companies Act 2006 and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

These financial statements were approved by the Directors and authorised for issue on 19th September 2015 and are signed on their behalf by

.....

Michelle Hough
 Chair

.....

 Date

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 in accordance with the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" (Revised 2005) and the Financial Reporting

Accordingly, the format of the profit and loss account has been amended, in order to present a true and fair view of the results of the company, as permitted by Section 396 of the Companies Act

(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.

Voluntary Income is received by way of grants, donations and gifts and is 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.

Governance costs include those associated with meeting the constitutional and statutory requirements of the Charity and include the independent examiners fees and costs linked to the strategic management of the Charity.

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.

Alström Syndrome UK
Financial Statements for the Year Ended 31st March 2015

Notes to the Accounts

2 Voluntary income

	Unrestricted funds	Restricted funds	2015 Total	2014 Total
	£	£	£	£
General Donations	27,611	0	27,611	32,476

3 Investment income

	Unrestricted funds	Restricted funds	2015 Total	2014 Total
	£	£	£	£
Bank interest receivable	1,698	0	1,698	676

4 Incoming resources from Charitable Activities

	Unrestricted funds	Restricted funds	2015 Total	2014 Total
	£	£	£	£
<u>Grants received</u>				
National Commissioning Grant	0	136,945	136,945	133,605
EU-WABB	0	8,929	8,929	0
Transition Activities	0	1,500	1,500	17,800
Asian Mentoring Scheme	0	0	0	29,722
Family Support	0	14,692	14,692	33,383
Research and development	0	1,039	1,039	22,766
	0	163,105	163,105	237,276

5 Costs of generating funds

	Unrestricted funds	Restricted funds	2015 Total	2014 Total
	£	£	£	£
Consultants costs	0	0	0	7,635
Administration costs	337	0	337	0
	337	0	337	7,635

Alström Syndrome UK
Financial Statements for the Year Ended 31st March 2015

Notes to the Accounts

6 Cost of Charitable Activities- by activity

	Unrestricted funds £	Restricted funds £	2015 Total £	2014 Total £
National Commissioning Grant	0	136,945	136,945	133,605
EU-WABB	0	8,929	8,929	32,131
Transition Activities	0	0	0	1,468
Asian Mentoring Scheme	0	13,074	13,074	13,549
Family Support	0	9,217	9,217	20,626
Research and development	0	0	0	83,153
Support costs	8,415	0	8,415	8,919
	<u>8,415</u>	<u>168,165</u>	<u>176,580</u>	<u>293,451</u>

7 Net incoming resources for the year

	2015 £	2014 £
Net incoming resources is stated after charging:		
Independent examiners' fee	<u>1,200</u>	<u>1,000</u>

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

	2015 £	2014 £
Other debtors	0	3,782
Prepayments & Accrued Income	<u>131</u>	<u>129</u>
	<u>131</u>	<u>3,911</u>

10 Investments

	2015 £	2014 £
Cater Allen Deposit	85,000	85,000
Virgin Deposit	<u>14,965</u>	<u>29,965</u>
	<u>99,965</u>	<u>114,965</u>

11

Creditors: amounts falling due

	2015 £	2014 £
Accruals	<u>7,208</u>	<u>1,000</u>

Alström Syndrome UK
Financial Statements for the Year Ended 31st March 2015

Notes to the Accounts

12 Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	Total funds £
Fund balances at 31 March 2015 as represented by			
Current assets	83,979	94,401	178,380
Current liabilities	(7,208)	0	(7,208)
	<u>76,771</u>	<u>94,401</u>	<u>171,172</u>

13 Unrestricted funds

	At 1 April 2014 £	Incoming Resources £	Outgoing Resources £	Transfers £	At 31 March 2015 £
General fund	62,100	29,309	18,599	2,826	75,636
Financial Assistance Grant Fund	0	0	0	1,135	1,135
	<u>62,100</u>	<u>29,309</u>	<u>18,599</u>	<u>3,961</u>	<u>76,771</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 to Alströmpatients and their families based upon an assessment of need.

Alström Syndrome UK

Financial Statements for the Year Ended 31st March 2015

Statement of Financial Activities

	Note	Unrestricted Funds £	Restricted Funds £	Total 2015 £	Total 2014 £
Incoming Resources					
Voluntary Income	2	27,611	-	27,611	32,476
Investment Income	3	1,698	-	1,698	676
Incoming Resources from Charitable Activi-	4	0	163,105	163,105	237,276
Total Incoming Resources		29,309	163,105	192,414	270,428
Resources Expended					
Cost of Generating Voluntary Income	5	337	0	337	7,635
Charitable Activities	6	8,415	168,165	176,580	293,541
Governance Costs		9,847		9,847	8,866
Total Resources Expended		18,599	168,165	186,764	310,042
Net Incoming/(Outgoing) Resources		10,710	(5,060)	5,650	(39,614)
Net Movement in Funds		10,710	(5,060)	5,650	(39,614)
Transfers between funds		3,961	(3,961)	0	0
		14,671	(9,021)	5,650	(39,614)
Total Funds Brought Forward		62,100	103,422	165,522	205,136
Total Funds Carried Forward		76,771	94,401	171,172	165,522

Alström Syndrome UK
Financial Statements for the Year Ended 31st March 2015
Notes to the Accounts

14 Restricted funds

	At 1 April 2014 £	Incoming Resources £	Outgoing Resources £	Transfers £	At 31 March 2015 £
National Commissioning Grant	0	136,945	136,945	0	0
EU-WABB	0	8,929	8,929	0	0
<i>Transition Activities</i>					
Allergan Foundation	16,200	0	0	0	16,200
St Jame'ss Place Foundation	10,000	0	0	0	10,000
Smaller restricted funds	2,032	1,500	0	0	3,532
<i>Asian Mentoring Scheme</i>					
Sylvia Adams Trust	24,528	0	13,074	0	11,454
<i>Family Support</i>					
Awards for All	8,992	0	0	0	8,992
Bradford and District CNET	2,013	0	0	0	2,013
Chloe Staddon Holiday & Equip- ment Fund	2,454	0	0	0	2,454
Genetic Disorder	3,144	0	0	0	3,144
Jeans for Genes	5,000	0	0	0	5,000
Sport England	0	9,740	7,411	0	2,329
Smaller restricted funds	9,892	4,952	1,806	(3,961)	9,077
<i>Research and development</i>					
One in a million	17,755	0	0	0	17,755
Smaller restricted funds	1,412	1,039	0	0	2,451
	103,422	163,105	168,165	(3,961)	94,401

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 Alströmpatients and their families.

Euro-WABB Project

Amount set aside to meet the Charity's contribution to an EU funded joint research project with two other related charities.

St Jame'ss Place Foundation

Funding towards a Transitions Coordinator

Sylvia Adams Trust

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

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 to Alströmpatients and their families.

Genetic Disorder

Amounts raised to provide holidays, outings and specific equipment to Alströmpatients and their families.

Sport England

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

Smaller restricted funds

Restricted grants and donations of less than £2,000

Notes to the Accounts

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, 5 (2014 3)Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustee meetings these claims totalled £2,927 (2014 £845)

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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.

Alström Syndrome UK
Independent Examiner's Report to the Trustees
Financial Statements for the Year Ended 31st March 2015

I report on the accounts of the company for the year ended 31 March 2015, which are set out on pages 12 - 19.

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
- 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

11 December 2015