



Alström Syndrome UK

Annual Report and Accounts For the year ended 31st March 2014



**Registered Charity Number 1071196
Registered Company Ltd by Guarantee No 3557191**

Alström Syndrome UK
31 Shearwater Drive
Torquay
Devon TQ2 7TL
Tel: 01803 613117
email: info@alstrom.org.uk
www.alstrom.org.uk

References and administrative information

Trustees

Michelle Hough (Chair)

Trevor Parkin (Vice Chair)

Mark Millais

Alexander Griffiths Rayson

Julie Beck

Dawn Mayes Appointed 1st July 2013

Curtis Vasey

Kez Hayat Appointed 1st August 2013

Chief Executive Officer

Kerry Leeson-Beevers (Position held until August 2013)

Trustees took on the Executive position from August 2013 onwards.

Registered Office

31 Shearwater Drive

Torquay

Devon

TQ2 7TL

Charity Number 1071196

Company Number 3557191

Bankers

Lloyds TSB, Paignton- Branch

Independent Examiners

Francis Clark LLP

Sigma House

Edginswell Park

Torquay

Devon

TQ2 7FF

Trustees/Directors report

Year ended 31st March 2014

The Trustees have pleasure in presenting their report and independently examined financial statements for the company for the year ended 31st March 2014.

The trustees' report and financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime and the requirements of the Statement of Recommended Practice on accounting and reporting for charities (revised 2005).

Alström Syndrome

Alström Syndrome is a very rare inherited condition which affects the body's metabolism with particular impact on all major organs including the heart, lungs, kidneys and liver. Dilated cardiomyopathy is often detected in young babies and often leads to premature death. Kidney failure may also occur. During childhood, patients suffer deteriorating eyesight which may include nystagmus and photophobia which often leads to blindness. Hearing loss and Type 2 diabetes is also common.

Because the condition unfolds gradually from birth and the different manifestations vary from individual to individual, correct diagnosis is often delayed leading to suboptimal treatment and a failure to anticipate future developments. There are presently just over 850 cases known worldwide, approximately 60 in the UK although the history of poor diagnosis referred to above almost certainly hides many more.

Structure, governance and management

Alström Syndrome UK is a registered charity and company limited by guarantee which was formed in 1998 after the founder Mrs Kay Parkinson's children were diagnosed aged 15 and 18. She was told it was extremely rare and only 12 other patients were then known. Over the past fifteen years the numbers known to the charity have grown to 60 and the charity has developed many services to support them. The major achievement has been the recognition by the NHS National Commissioning team of the excellence of the multi-disciplinary clinics which have been set up by the charity in conjunction with Birmingham Children's Hospital and the Queen Elizabeth Hospital, Birmingham for adults. These clinics are the first in the world for this condition.

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.

At the quarterly Trustees meetings the board agree the broad strategy and areas of activity for the charity, which have taken account of families and patients views and opinions which are always sought at the Annual Family Conference. The day to day running of the charity is delegated to the Chief Executive until August 2013 when the Trustees took the Executive position.

The Trustees are assisted from time to time with input from Professor Timothy Barrett clinical lead for the Alström's children clinic at Birmingham Children's Hospital and Dr Tarek Hiwot adult clinical lead at the Queen Elizabeth Hospital, Birmingham and Trustees would like to formally express their gratitude for their dedication to Alström patients. The Alström Syndrome multi-disciplinary clinics have now moved successfully across to QEH from Torbay Hospital and are making significant progress in treatments, diagnosis and pioneering research.

Trustees all undergo 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 and Charities and Public Benefit"

Trustees give of their time freely and are required to disclose all relevant interests and register them with the Chief Executive and in accordance with the charities policy withdraw from decisions where a conflict of interest arises.

Funding Structure

The charity has a service level agreement with the National Commissioning Group (NHS England) to provide national co-ordination of the multi-disciplinary clinics and family support. ASUK organises families' accommodation and helps with travel arrangements. We also agree to maintain the web site with the latest medical information and circulate clinic dates. ASUK also agree to provide medical information in the newsletter. The charity reports monthly to the NCG about these activities.

Grants have been obtained to fund the Asian Mentoring Scheme and Support Transition. All monies raised by families go into a separate account and is used solely for their use. From January 2011, ASUK received funding from the EU as a partner in an EU WABB (Wolfram, Alström and Bardet Biedl) project.

The charity currently has reserves of £114,965.00 (as of 31st March 2014) £85,000 is invested in a Cater Allen Term Deposit Account and £29,965.00 is invested in a Virgin Charity Deposit Account. These reserves are to ensure the charity is sustainable into the future and it also enables the day to day running of the charity to operate.

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.

Over the year Alström Syndrome UK has worked towards its charitable objectives in the following ways:

- providing advice and support to those affected by Alström Syndrome and /or their families to help them access the disability benefits to which they are entitled
- offering an individual advocacy service through home visits ,face to face meetings, support at multi-agency meetings, in writing, by telephone or e-mail in areas of special educational need, independent living and care needs
- arranging activity holidays
- organising a National Conference
- organising a medical and scientific conference
- providing grants in cases of hardship
- funding research

Alström Syndrome Clinics



Until 2006, the Alström Syndrome condition was managed on a voluntary basis usually alongside the annual family conference by doctors who were willing to give their time freely to help patients. In 2006 Birmingham Children's Hospital and Torbay Hospital received funding from the National Specialised Advisory Service which is now named NHS England. This designation changed overnight the provision of services to Alström patients from ad hoc clinics to well organised multi-disciplinary clinics which are held quarterly. Alström Syndrome UK charity was funded as an equal partner in the service in 2008.

In 2012, the adult clinics moved successfully to the Queen Elizabeth Hospital, Birmingham from Torbay Hospital. The Trustees would like to express their thanks to all the professionals involved at Torbay Hospital in making this transfer a success.



2013 has been a very exciting year for Alström Syndrome UK. There has been many positive changes with ASUK and the Board of Trustees who are now taking a more proactive and executive approach to move the charity forward.

In August 2013, the Trustees decided to take on the executive role of the charity to really understand the workings of the charity, ways we could improve and remain strong to our cause and objectives.

The Trustees will continue to work alongside the ASUK Contractors to ensure families receive the support and help they need alongside promoting awareness and looking at new and pioneering research projects.

With this new approach, Kay Parkinson has been able to move her focus onto collaborating with specialists, researchers and funding partners across Europe and worldwide.

We hope this will lead to better treatments, research and clinical trials which could improve the lives of people affected by AS.

With the funding we have been able to generate it has been with great pride that so many families are now able to experience activities which they never thought possible. Including providing events such as the ASUK Family Week in Torquay which enabled families from across the UK to come together and support one another.

Alström Syndrome UK continue to grow from strength to strength, supporting families, enabling activity trips for children to experience activities which they never thought would be possible and growing sustainable through grant funding. One of the major highlights this year was gaining the EURORDIS Patient Organisation Award 2013. This is in recognition of all the hard work which ASUK have achieved for patients and their families across Europe.

It is an honour to now be in a position to ensure that families like ours are fully supported, and to be able to work together with the families, medical professionals and researchers to push for treatments for the wide range of conditions that Alström Syndrome presents.

Alström Syndrome UK is still a life limiting condition, presenting with a wide range of devastating symptoms. The specialised clinics ASUK initiated and deliver in partnership with the Hospitals have proved their effectiveness showing an increase in life expectancy for those diagnosed; we still however have a long way to go to ensure everyone affected in the UK is diagnosed.

Alström Syndrome UK continues to grow due to the passion and personal dedication of our team, as a patient led charity we continue to have the patients at the forefront of our thoughts.



This has been a very busy year with many new opportunities arising since standing down as CEO.

Primarily I was able to focus on disseminating information on Wolfram, Alström and Bardet Biedl (WABB) diseases as this was the busiest time for us in the final year of the WABB project. Without the continued support of John Parkinson this manic year would not have been possible.

As Alström Syndrome UK (AS UK) was voted EURORDIS Patient Organisation 2013 we were invited to many conferences to speak about our organisation, how it was set up and how it is funded. Organisations want to know how NHS funding was obtained. This also gave the opportunity to talk about the EUWABB project and disseminate information.

The first IRDiRC Conference was held in Dublin, Ireland on 16-17 April 2013 and was organised by the European Commission in association with the Irish Presidency of the European Union. The conference aimed to gather stakeholders active in the rare disease area from across the globe. In addition to a top-level programme taking stock of advances toward IRDiRC goals, it provided ample opportunities to network with the international rare disease community. I was fortunate to be present and to be able to disseminate information on WABB diseases

The 9th World Paediatric Endocrinology meeting in Milan 19-22nd September 2013, where we had a EUWABB stand was a great success with all the guidelines on WABB diseases being disseminated. This event offered a great opportunity to target the many professionals working in endocrinology and lots of new contacts were found.

The World Orphan Drug Conference in Geneva 14-15th Nov 2013 where information and posters were displayed attracted the attention of Prometics Pharmaceuticals who have developed an anti-fibrosis drug treatment and were keen to trial their drug on the skin samples that AS UK had taken under a Big Lottery Grant.

I was also given the opportunity to talk at the Findacure Conference in January 2014 in London - this is a new organisation being set up aiming to find cures for rare diseases. The EU WABB project was discussed and attracted interest from other groups wishing to apply for EU funds.

I was fortunate in having a proposal to the London School of Economics on the cost benefits of multi-disciplinary clinics for rare diseases accepted. This resulted in six students being available to work on analysis/benefits for patients and doctors of multi-disciplinary working. The final report is useful for education for health professionals as to the benefits not only of professionals working in a multi-disciplinary way but also of the benefits of patient involvement at all levels of the process. The group presented their findings on 29th April at the LSE.

Through the contacts made in EU WABB it has also been possible to now develop Alström Europe and an EU wide meeting was held in Brussels at the University of Birmingham's Offices on 27th February 2014 to discuss an Horizon project PHC 26 that is being developed. This project if successful will form a business model for

other rare diseases to work pan- EU wide using Mhealth applications. A meeting with Orange Healthcare who are partnering in the project was held with Prof Helen Dollfus to discuss using Alström Syndrome as a pilot. Alström Syndrome was chosen as the disease affects most organ systems and Orange were keen to be able to use as many of the M health devices as possible for the pilot so that they could develop a robust business model. The application was submitted on 13th April 2014.

I have been invited to join the Patient Association Committee (PAC) of RD Connect and this offered further opportunities at the RD Connect meeting in Heidelberg 22-26th February to disseminate information about EUWABB diseases and raise awareness of the many issues affecting rare conditions. Particularly discussed were issues around consent and patients being fully aware of what they are consenting to, and "ethics" forming a barrier to research. The experience of AS UK and the Big Lottery grant was discussed.

I also spoke at the RE (Act) Conference 5-8th March 2014, 2nd international Congress on Research and Rare and Orphan Diseases in Basel, Switzerland. This conference brought together researchers from around the World to discuss the latest results in the field of Rare and Orphan Diseases. A stand was available free of charge as I was speaking and leaflets were distributed on WABB diseases.

John and I have continued to uphold the NHS clinical contract and attend the adult clinics and offer on-going support to adult families as and when needed, we believe the service is enhanced through wider contacts and information on possible new drug therapies from across the EU and Internationally. An excellent on-going EU and Australian collaborative network has been developed and maintained with QEH and BCH and Alström Europe which we believe will grow over the next year.

Dr Segolene Ayme- founder of Orphanet was the independent assessor of the EU WABB project "EURO-WABB was an ambitious and risky project as it addressed three very rare genetic diseases having in common to include diabetes among other phenotypic expressions of the disease but managed by different communities which needed to be brought together. Overall the project ended very successfully despite the short time span of such a project."

EUWABB was a considerable additional workload on top of our already heavy workload, necessitating many weekends away and evening working to ensure we met EU WABB reports, deadlines and conferences.

The experience has enabled the formation of AS EU and on-going Pan-EU collaborations with both Queen Elizabeth Hospital and Birmingham Children's hospital- vital for an ultra rare disease such as Alström Syndrome.

Kerry Leeson-Beevers

Alström Syndrome UK, Acting Chief Executive Officer March 2013 – August 2013

Alström Syndrome UK, National Development Manager August 2013 – March 2014



2013 – 2014 has been a very busy and successful year; I have enjoyed the opportunity of briefly taking on the role of Acting Chief Executive Officer and now hand the reigns over to the ASUK Board of Trustees who will take on the Executive position. As a team, we will support them fully in this role.

I continue to thoroughly enjoy my role within ASUK and I am extremely proud of our achievements this year. As my role is to develop the charity as a whole, it is important that I oversee all contracts, particularly our contract with NHS England. I work closely with our NHS partners in Birmingham and ensure families' needs are met and services are provided in line with our service specification. We continue to seek improvements where possible and will always consult with our families to ensure we remain patient led.

I work closely with Birmingham Children's Hospital and attend all children's clinics. I am also invited to post clinic meetings with the team to fully evaluate the service and discuss any areas for improvement. I work closely with local health, social care and education professionals to ensure everyone is working together, has the relevant information in order for them to fully support our families and provide additional training and advice where needed.

I have been working with the team at QEH to improve support for young adults and we are planning an extended young adult clinic in May 2014. Our young adults are supporting us to develop this new clinic by completing in depth questionnaires and they have had discussions with me to enable us to determine areas where additional support is needed.

With much appreciation, we have received a grant from St James's Place to allow us to develop services throughout transition and we continue to work closely with Marie McGee, Transition Coordinator at BCH.

I have been raising awareness throughout the UK and Europe to highlight the needs of our families alongside raising the profile of Alström Syndrome. We do hope that our efforts in this area will help identify any new patients and alert people to the symptoms of Alström Syndrome. We are receiving requests from around the world to attend our clinics and one family have travelled all the way from Australia! They were extremely impressed by the Alstrom service and we will continue to support them wherever we can.

We hope that our interventions will aid quicker diagnosis, so that patients have the opportunity to attend our specialized multi-disciplinary clinics. We have already seen a decrease in the average age of diagnosis, this is encouraging and we do hope that our effort in raising awareness is making an impact.

Thanks to Jeans for Genes who have kindly funded us to produce a DVD entitled 'Living with Alström Syndrome'. This has been another successful project and the DVD has now been produced in five different languages and is available in DVD format as well as on our You Tube Channel.

We have been successful in obtaining year 3 funding for the Asian Mentoring Scheme thanks to the Sylvia Adam's Trust and I continue to oversea this project. Sylvia Adam's have been amazing supporters of this project and I would personally like to thank them on behalf of ASUK for their generosity and their faith in us.

I have recently become a member of the Council for Disabled Children and I continue to represent EURORDIS on the Paediatric Committee at the European Medicines Agency. I have attended numerous conferences and events to further increase my knowledge of relevant issues, policies and changes in legislation that affect families.

We continue to support families by applying for grants, providing equipment and organising enjoyable activities for individuals and families. We hope to plan more of these in the coming year as families do comment on how much they enjoy spending time together.

Despite the changes in my role, my direct work with families is what matters most to me. While I may not visit families as regularly as in previous years, please rest assured that all of the work I do behind the scenes is to move our charity forward and ensure that as a team, we are providing the very best support we can. As a charity, we continue to have a very positive reputation within the field of rare diseases and I firmly believe this is because we are all extremely passionate about our work and believe in what we are aiming to achieve.



It has been another busy year and as always it has been a great privilege to support families who are affected by Alström Syndrome, as this is at the heart of everything ASUK stands for.

It has also been a pleasure to support families through a variety of activity breaks which have enabled youngsters affected by Alström Syndrome to experience an exciting range of activities, providing fun, relaxation and confidence building. These breaks have included Calvert Trust Activity Centre, Drayton Manor Theme park, Chessington Theme Park and the ASUK Family Week in Torquay which enabled many families to get together; as the condition is ultra rare it can be very isolating.

Many families have taken part in the PossAbility project which was made possible due to a Lottery grant. This project supported people who wished to find volunteering opportunities in their own local area. Many placements were found including in a school language department, Goat Sanctuary, retail establishments and many more. Many of these placements have now been offered on a permanent basis. Next year we will be providing support and tandems for families to engage in cycling which has been made possible through a Sport England grant.

Awareness raising has been an important part of my current role and this has been achieved through a monthly e-newsletter, a newly developed website, with includes regular updates for both families and professionals alike and updates via social media.

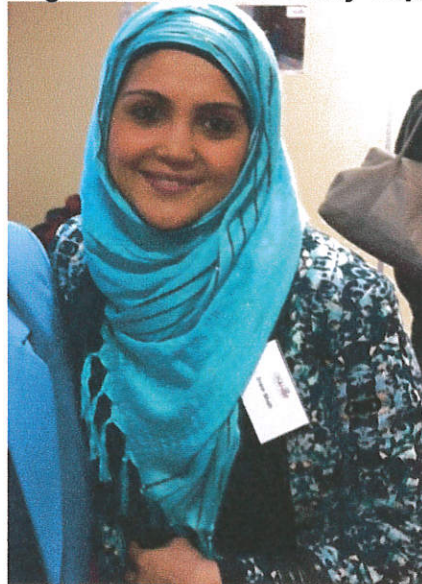
I have continued to work closely with the Inherited Metabolic Team at the Queen Elizabeth Hospital, Birmingham to ensure that the AS adult clinics run smoothly and the patients needs and accommodation provisions are met.

In 2013, the first ASUK calendar was produced which showcased precious images of children and young people who are affected by Alström Syndrome. This enabled ASUK to raise funds for families, gain sponsorship and raise awareness of this ultra rare condition. Our thanks go to the very kind support given by our sponsors; Retro Box Gifts, New College Worcester and Hear First Training.

I will continue to strive to promote the needs of people affected by Alström Syndrome and support all Trustees and Contractors in their roles.

Iram Shah

Alström Syndrome UK, Asian Mentoring Assistant and Family Support Worker



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 have found that empowering parents by attending annual review meetings alongside them has led to an increase in patient confidence and empowerment.

The new special needs document is a tool for all contractors to keep a track on the special needs requirements our young people may have in education. I have enjoyed working on this document and I am hopeful it will make a positive difference within the educational settings. I am currently studying an MA in education which can be challenging at times however I am positive that my contribution with the knowledge taken from my MA will make a huge difference to all our young people in education.

I am looking forward to working alongside Kez Hayat and Kay Parkinson on the Alström Asia project in 2014 which will widen the search in finding Alström patients in Asia, which will lead to finding the numbers required for a clinical trial. I have attended numerous conferences this year alongside patient group meetings and enjoy delegating with professionals from health and educational settings.

I will continue to meet the needs of all our families and raise awareness of Alström Syndrome.

Fundraising Report **Catherine Lewis MInstF**

Despite a continually challenging financial environment Alström Syndrome UK has continued to generate funds through grant making trusts, family fundraising and grant applications.

Through the efforts of our Fundraiser Julia Scott, Trusts and Foundations have continued to support ASUK. In particular, the Asian Mentoring Scheme has been very well supported by many Trusts such as the Sylvia Adams Trust and also the transition project has generated sustainable funding. Also many have supported the continuation of the activity breaks for children and young people.

Families have continued to support Alström Syndrome UK and this has enabled the charity to provide activity breaks for young people and special memories for families. This has been possible through many fundraising events such as marathons and local events such as the Exeter Police and Community Choir evening which raised £506.10

Grants have been successful from Sport England to enable families to experience cycling through tandems and adapted trikes alongside our support, which will continue into 2014. Funding from the National Lottery has also enabled the PossAbility project to go ahead to enable individuals to experience volunteering opportunities in their local area.

The Trustees of 'ASUK' are extremely grateful for all the volunteers who give their time freely to support the charity and all the families who continue to support our great cause. The generosity of individuals, companies and charitable trusts and foundations have helped the charity continue its vital work. Our heartfelt thanks go to everyone who has supported ASUK throughout the year, without this support our work would not be possible.

Development of Research

Big Lottery Funded Research Project "Bringing Hope to Alström Patients" July 2010 - July 2013

In 2009, the Big Lottery Fund awarded ASUK £344,232 to lead this 3 year research project into Alström Syndrome. The project got underway in July 2010 together with our partners, South Devon NHS Trust, Birmingham Children's Hospital NHS Trust and Cambridge University Institute of Metabolic Science, we have begun the most comprehensive study of Alström Syndrome ever undertaken. Uniquely, this project combines clinical studies with basic cell biology investigations.

This is a unique collaboration which will deliver:

- The first wide ranging, structured research programme into Alström Syndrome
- The first national clinical database of Alström Patients
- The first Alström Syndrome tissue bank
- The first ever stem cell research into Alström Syndrome

Importantly we expected

- to discover more people who have never before been correctly diagnosed with AS and therefore not been given the best treatments
- To be able to improve management of this difficult to treat condition
- To be able to better predict the course of the disease
- To take the first steps to genetically engineered treatments


The Big Lottery research project finished in December 2013 and although the process of ASUK gaining access to the clinical database has been challenging, we can now move forward on a positive note. The Queen Elizabeth Hospital are working towards the information and database being transferred to the QEH so that all relevant professionals can gain access and continue the research for further development.

We would like to say thank you to all patients who have given their time to this research project. Families still want to be actively involved in these studies and skin biopsies are still being donated which have been sent to Cambridge University where they can be successfully made into cell lines.

This research and data will be developed alongside AS EU so we can correlate more information to enable future treatments and better management of this devastating condition.

Report Signed on behalf of the Board of Trustees

Signature



MICHELLE HOUGH (CHAIR)

Date 2nd December 2014

Alström Syndrome UK Statement of Financial Activities
For the Year Ended 31st March 2014

Statement of Financial Activities	Unrestricted Funds	Restricted Funds	Total 2014 Funds	Total 2013 Funds	Note
	£	£	£	£	
Incoming Resources					
Voluntary Income	32,476	-	32,476	85,910	2
Investment Income	676	-	676	1,906	3
Incoming Resources from Charitable Activities	-	237,276	237,276	257,326	4
Total Incoming Resources	33,152	237,276	270,428	345,142	
Resources Expended					
Cost of Generating Voluntary Income	7,635	-	7,635	16,492	2
Investment Management Costs	35	-	35	221	3
Charitable Activities	7,039	284,532	291,571	329,570	4
Governance Costs	8,866	-	8,866	3,584	5
Other Resources Expended	1,935	-	1,935	3,860	6
Total Resources Expended	25,510	284,532	310,042	353,727	7
Net Incoming/Outgoing(-) Resources	7,642	-47,256	-39,614	-8,585	
Net Movement in Funds	7,642	-47,256	-39,614	-8,585	
Reconciliation of Funds					
Total Funds Brought Forward	54,458	150,678	205,136	213,721	
Movement in Funds	8,642	-47,256	-39,614	-8,585	
Total Funds Carried Forward	63,100	103,422	165,522	205,136	

All of the above results are derived from continuing activities. All gains and losses recognised in the year are included above. The surplus for the year for Companies Act purposes is equivalent to the net movement in funds.

The notes on pages 14 to 17 form part of these financial statements.

Alström Syndrome UK Balance Sheet as at 31st March 2014

Balance Sheet	2014	2013	See Note
Current Assets			
Debtors	3,911	5,131	10
Investments	114,965	135,000	11
Cash at Bank & in hand	47,646	81,961	12
Total Current Assets	166,522	222,092	
Liabilities			
Creditors - amounts falling due within 1 year	1,000	16,956	13
Net Assets	165,522	205,136	
The Funds of the Charity			
Brought Forward Total Funds	205,136	213,721	
Movement in Funds	-39,614	-8,585	
Carried Forward Total Funds	165,522	205,136	
Analysed by;			
Restricted Funds	103,422	150,678	14
Unrestricted Funds	62,100	54,458	14
	165,522	205,136	

These financial statements were approved by the directors and authorised for issue on 2nd December 2014 and are signed on their behalf by


MICHELLE HOUGH (CHAIR)

Company registration number 3557191

These financial statements have been prepared in accordance with the special provisions for small companies under Part 15 of the Companies Act 2006 and with the Financial Reporting Standard for Smaller Entities (effective April 2008)'.
The notes on pages 14 to 17 form part of these financial statements.

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 20C and the Financial Reporting Standard for Smaller Entities (effective April 2008) ("the FRSSE").

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 2006.

(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 qualified 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.

2. Voluntary Income - Income relates to the monies kindly donated by individuals and charitable organisations either for specific purposes (restricted funds) or for the general benefit of the Charity (unrestricted funds). Expenditure relates to the cost of engaging a professional fundraiser to generate such income.
3. Investment Income & Costs. Interest earned on monies invested with various investment organisations (Note 10) against the costs of organising and accounting for these investments.
4. Charitable Activities - The majority of the Charity's activities are funded by specific grants and donations, the main ones are:
 - (a.) National Commissioning Group - funds the service agreement between the Charity and the National Commissioning Group. This allows the Charity to maximise access to NHS services and provide support and information to Alstrom patients and their families
 - (b.) Big Lottery - to fund major research into Alstrom Syndrome over a three year period.
 - (c.) One in a Million Fund - a fund established with a long-term aim of raising £1m for future research into Alstrom Syndrome.
 - (d.) Various donations to fund the extension of the Charity's work into the Asian community to identify, support and assist new patients and bring them under the umbrella of Alstrom Syndrome's support network.Other major donors and details of Income and expenditure for each category is fully detailed under Note 15
5. Governance Costs - costs relating to the running of the Charity as opposed to the direct management function.
6. Other Costs - relate specifically to the cost of providing financial assistance to support to patients in need.

Alström Syndrome UK – Notes to the Statement of Financial Activities & Balance Sheet
Year Ended 31st March 2014

Note 7 - Resources Expended				
This is stated after charging the following services which are engaged on an external contract basis. These external contracts are made up of 4 full time members and 3 part time members of the team.				
		2014		2013
Executive Services		48,900		53,900
Family Liaison Services		29,700		29,740
Special Needs Services		30,660		55,792
Child Development Services		10,375		22,747
Financial & Administrative Services		7,866		6,065
Professional Fund Raising Services		7,635		10,208
Total		135,136		178,452

8. Trustee Remuneration & Third Party Transactions. 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 Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustee meetings these claims totalled £845.81
9. The Charity is exempt from tax on income and gains to the extent that these are applied to its charitable objects.
10. Debtors. The amounts included in Debtors relate to balances owing from Alstrom Europe £3,782 (2013:£5,000) and prepayments of £129 (2013: £131).
11. Investments. These balances relate to funds held with institutions to provide a return for the Charity
Cater Allen - Deposit Account £85,000 (2013 : £85,000)
Virgin Deposit Account £29,965 (2013 ; £50,000)
12. Cash. Monies held in various bank accounts for investment and to meet the day to day requirements of the Charity.
13. Creditors - relates to accruals and deferred income due within the next financial year.

Alstrom Syndrome UK

Financial Statements for the Year Ended 31 March 2014

Note 14 - Fund Balances held by the Charity at 31st March 2014

	Balance 1st April 2013	Grant in Year	Expenditure in Year	Balance 31 March 2014
National Commissioning Grant	-	133,605	133,605	-
Big Lottery	63,864	20,701	83,153	1,412
EU-WABB	32,131	-	32,131	-
	95,995	154,306	248,889	1,412
Other Restricted Grants & Donations				
<i>Transition activities</i>				
Albert Hunt Trust		1,000	587	413
Allergan Foundation	10,000	6,200	-	16,200
Hospital Saturday Fund		1,000	587	413
Lynn Foundation		500	294	206
St James's Place Foundation		10,000	-	10,000
Sovereign Healthcare	1,000		-	1,000
<i>Asian Mentoring Scheme</i>	-		-	-
Sylvia Adams Trust	8,355	29,722	13,549	24,528
<i>Family Support</i>			-	-
Austin & Hope Pilkington Foundation	1,000		587	413
Awards for All		8,992	-	8,992
Barbara Shuttleworth Memorial		1,000	587	413
Bradford and District Cnet		4,875	2,862	2,013
Carmen Butler Charteris CHARITABLE TRUST	2,000		1,174	826
Chloe Staddon Holiday & Equipment Fund	5,944		3,490	2,454
Constance Green	1,000		587	413
Douglas Arter Foundation		500	294	206
Financial Assistance Grant Fund	2,750		1,615	1,135
Genetic Disorder		7,616	4,472	3,144
Jeans for Genes		5,000	-	5,000
JK Stirrup Charitable Foundation	1,000		587	413
Millichope Foundation	2,000	2,000	1,174	2,826
Norman Family Foundation		500	294	206
Rank Foundation		1,000	587	413
Simply Health	2,807		1,648	1,159
Sir Jules Thorn Charitable Trust	1,137	1,000	668	1,469
Sport England (March 2014-March 2015)			-	-
<i>Research and development</i>			-	-
One in a Million	15,690	2,065	-	17,755
Total Restricted Grants & Donations	150,678	237,276	284,532	103,422
Non-Restricted Grants & Donations	54,458	33,152	25,510	62,100
including for information				
Capita Business Services		4,250		
	205,136	270,428	310,042	165,522

14 Restricted Funding Notes:

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.

Big Lottery Funding – balance of grant (reference C165AA1447) received to fund major research into Alström Syndrome over a three year period ending July 2013.

Euro-WABB Project – amount set aside to meet the Charity's contribution to an EU funded joint research project with two other related charities.

One in a Million Fund – a fund established with a long term aim of raising £1 Million for future research into Alström Syndrome.

Chloe Staddon Holiday & Equipment Fund – amounts raised to provide holidays, outings and specific equipment to Alström patients and their families.

Financial Assistance Grant Fund – amount set aside to provide financial support to Alström patients and their families based upon an assessment of need.

Sylvia Adams Trust – funding towards the Asian Mentoring Scheme which works specifically within Asian communities to offer support and raise awareness.

Jeans for Genes Funding – funding to produce an information DVD on living with Alström Syndrome.

Sport England Funding – funding to enable the purchase of tandems and specially adapted trikes.

Donations for Specific Purposes are those that are kindly donated to fund particular Charity activities and/or groups of patients. Such as Transition activities to work specifically with young people moving onto adult services and supporting them through this process.

Company 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 1985, 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.

The report has been prepared in accordance with the provisions available to companies entitled to the small companies exemption.

Financial Statements Signed on behalf of the Board of Trustees

Signature



MICHELLE HOUGH (CHAIR)

Date 2nd December 2014

Alstrom Syndrome UK

Independent Examiner's Report to the Trustees

Year ended 31 March 2014

I report on the accounts for the year ended 31 March 2014, which are set out on pages 12 to 17.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's 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. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Institute of Chartered Accountants in England and Wales.

It is my responsibility to:

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

Basis of independent examiner's statement

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 the trustees concerning any such matters. The procedures undertaken do not provide all of 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 statement below.

Independent examiner's statement

In the course of 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 Section 130 of the 2011 Act; and
 - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Acthave 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.



R J Hussey BSc FCA
Francis Clark LLP
Chartered Accountants
Sigma House
Oak View Close
Torquay

23 December 2014