

COMPANY REGISTRATION NUMBER: 3557191
CHARITY REGISTRATION NUMBER: 1071196

Alstrom Syndrome UK
Company Limited by Guarantee
Unaudited Financial Statements
31 March 2019

THOMAS WESTCOTT
Chartered Accountants
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Alstrom Syndrome UK
Company Limited by Guarantee
Financial Statements
Year ended 31 March 2019

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Alstrom Syndrome UK

Company Limited by Guarantee

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

Year ended 31 March 2019

The trustees, who are also the directors for the purposes of company law, present their report and the unaudited financial statements of the charity for the year ended 31 March 2019.

Reference and administrative details

Registered charity name Alstrom Syndrome UK

Charity registration number 1071196

Company registration number 3557191

Principal office and registered office 4 St Kitts Close
Torquay
TQ2 7GD
Devon

The trustees

Trevor Parkin	Chair
Dawn Mayes	Vice Chair
Alexandra Griffiths-Rayson	
Kez Hayat	
Michelle Hough	(Resigned 5 April 2019)
Dr Richard Paisey	
Parminder Singh Jutla	(Resigned 6 June 2019)
Dr Richard Steeds	(Resigned 3 December 2018)

Independent examiner Stephen Cresswell BA FCA DChA
Thomas Westcott Chartered Accountants
47 Boutport Street
Barnstaple
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Alstrom Syndrome UK

Company Limited by Guarantee

Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2019

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

The organisation is a charitable company, limited by guarantee, incorporated on 1st May 1998 and registered as a charity in the UK on 25th August 1998. The company was established under a memorandum of association which established the objectives and powers of the charitable company and is governed under its articles of association.

Recruitment and appointment of trustees

The directors of the company are also charity trustees for the purposes of charity law.

New trustees are appointed by the existing trustees and serve for three years after which they put themselves forward for re-appointment. Trustees can serve a maximum of three terms of three years, a total of nine years at which point they must resign from the board. They can serve on an ASUK patient advisory or project group after this.

Induction and training of trustees

New trustees are given a copy of the memorandum and articles of association and are given copies of the Charity Commission guidance "The Essential Trustee: What you need to know"

New trustees have a six-month induction period during which they can be assigned a trustee mentor who can provide advice and guidance. New Trustees receive an induction pack containing key information to gain a further understanding of ASUK and its' strategic priorities. They are invited to meet with the Chief Executive and the staff team as well as patients and their families.

OBJECTIVES AND ACTIVITIES

Public benefit

The trustees have complied with section 4 of the Charities Act 2006 in regard to the public benefit requirement. During the year, we have:

1. Represented patient's views by campaigning and lobbying government working collaboratively with other rare disease patient groups and organisations. ASUK joined over 125 patient organisations signing the Rare Disease UK's open letter, asking the Government to review and refresh the UK Strategy for Rare Diseases. This coincided with Rare Disease Day and was sent to Baroness Nicola Blackwood, the Minister in charge of rare diseases.
2. We continue to work with others to hold the government to account against its' 3 rare disease care promises; Every person with a rare disease will have a dedicated person responsible for coordinating their care. Every patient with a rare disease will be given an 'alert card', including information about their condition, treatment regime and contact details for the individual expert involved in their care. Every child with a rare condition will be transferred to appropriate adult services when they reach the age of 18, even if that adult service is not the commissioning responsibility of NHS England.

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2019

3. Our Family Support team has continued to provide advice and information to patients and their families at specialist NHS clinics, visited patients and families at home and in schools, colleges and Universities helping with practical challenges. In addition, we have encouraged and supported self-advocacy to enable families to navigate the complex health, social care and education system. We advocate for those who struggle to represent themselves whether through barriers such as language, culture and intellectual disability. The family support team have visited 53 families at home and supported 35 students at school, college or University.
4. We achieved 100% attendance with patients attending clinic, a proud achievement and the only patient led organisation to consistently achieve this every year. We supported 60 adults and children, at 11 multidisciplinary clinics.
5. The Breaking down Barriers Project has increased its' capacity with rare disease charities increasing its reach and continuing to develop good practice around inclusive approaches. We have employed a Community Coordinator to continue to grow this project. We were invited to speak at the Conservative Muslim Forum (CMF) which brought together expert speakers at the House of Lords to discuss the issues affecting Britain's Muslim communities and to share the experiences of Britain's Jewish communities.
6. The board have invested the one in a million fund to lead a major piece of work into the creation of a patient registry.
7. We continue to disseminate evidence based information to professionals and others who work with individuals and their families that are affected by Alström Syndrome. Increasing our social media presence and using cost effective ways to disseminate information the website received over 32000 unique visitors during 2018/2019.
8. We launched the Big Activity Challenge to fund special activities and experiences to enable and empower adults with Alström. We also provided small grants for fitness related activities and equipment.
9. The research consortium developed and designed an Early Years survey to learn more about diagnosis, symptoms and experiences in the under-fives.
10. Children and young people have enjoyed theatre visits, flying experiences and learnt cooking skills with the ASUK Food Friends Active Club.
11. Trustees attended an away day focussing on the role of a Trustee with Cranfield Trust.
12. Trustees and staff enjoyed an away day together discussing achievements and future directions.

Objectives and activities

Purposes and aims

Alström Syndrome UK's objectives, as set out in the company's memorandum of association, are to;

1. 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 their families, carers and those working with affected individuals.
2. The promotion of research into Alström Syndrome and related syndromes in the UK and abroad and the public dissemination of the useful results thereof.

Alstrom Syndrome UK

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2019

ACHIEVEMENTS AND PERFORMANCE

Chairs Review

I am pleased to introduce our annual report and accounts for 2018/2019

This is my second Chairs Review and I'm pleased to be able to report on the many achievements in the year against what can only be described as a challenging funding landscape for all charities, particularly for a small organisation that supports patients and families with an ultra-rare disease.

Last year I reported on our recruitment drive, this year I am sad to say that due to unforeseen circumstances two Trustees have resigned. We are grateful to both Rick Steeds and Parminder Jutla-Singh who, in their brief tenure, made an enormous contribution to ASUK. This issue of Trustee recruitment was addressed at a Trustee Training and Development day in March 2019 and we began a new optimistic and enthusiastic recruitment drive in March 2019, paying attention to both targeting potential new Trustees, encouraging the board to suggest candidates and advertising to a wider audience.

The board members in 2018/2019 remain a balanced mix of professionals and individuals with Alström or with a child with Alström syndrome. This continues to enable the board to be a truly representative patient led organisation, serving families and their loved ones.

This year we have made some huge steps forward, focusing on our long-term strategy of increasing research opportunities, continuously improving the support that we offer families and developing robust evidence based resources to inform and educate our many different audiences. The board decided to invest in a long term aim of developing a patient registry and are pleased to be supported by the Centre of Rare Diseases at Sanford University. This is the beginning of a long-term objective that begins to connect patients globally and to this end we have begun conversations with international Alström patient groups to develop 'Global Alström'. During the year, we had four newly diagnosed patients, two adults and two children, a key aim is to identify what are the key factors that lead to a diagnosis.

We continue to support patients and families at clinics. Supporting the transition of younger patients, as they move from children to adult clinics, supporting patients taking part clinical trials and delivered individual family and person centred support throughout the UK. We have been delighted to launch our Big Activity Challenge aimed at adults, funded sports and exercise equipment and organised fun events for families, children and young people, including flying lessons for one adventurous young adult!

Our website and social media presence is expanding with more visitors from all 4 corners of the globe with many of our resources being shared nationally and internationally. I think it can be said it has been an exceptionally busy and successful year!

Alstrom Syndrome UK

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Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2019

Financial position

The Trustees are confident that we operate to make effective use of our limited resources. The trustees monitor levels of reserves and planned expenditure closely to ensure that the Charity is managing our limited reserves to the best benefit of the Alström family. The board continues to ensure we operate in a compliant manner.

The trustees are pleased to report small surplus of £9,778 for the year. The General Fund stands at £85,093.

Finally, a big thank you

I would personally like to thank the board for their continued commitment, our Chief Executive Ann Chivers and the staff team for their hard work, enthusiasm and dedication to making a difference to the lives of people and their loved ones with Alström Syndrome. I would also like to thank the extraordinary clinicians and professionals who work tirelessly to encourage and support individuals and families.

The work we all do is making a difference, none of which is possible without the generous support of families and friends, supporters and funders, clinicians and professionals. We are extremely grateful to one and all.

Key Achievements and performance

During the year, we have:

- Supported individuals to navigate what can be a complex and difficult social services system to ensure they get the benefits they are entitled to.
- Built upon our knowledge and understanding to further develop a careful and considered transition pathway with young people moving into adult services.
- Continued to provide emotional and practical support for individuals and their families who are experiencing difficulties.
- Made improvements to the service at clinics based on patient feedback.
- Acted prudently and resourcefully to ensure we control expenditure and make the most of income and donations.
- Used social media and other communication channels to increase our reach.
- Enabled peer to peer connections.
- Launched the Big Activity challenge to encourage self-advocacy.

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Year ended 31 March 2019

- Encouraged healthy lifestyles with children, young people and adults, providing exercise equipment and gym memberships.
- Developed the Foodie Active Friends Club to include physical activities, aimed at helping children and young people make healthy choices, learn to cook and be active.
- Recruited new staff to begin growing the Breaking Down Barriers project
- Developed collaborative partnerships around key areas of common interest with the intention of working together on projects.
- Successfully bid for Children in Need grant to deliver transition services and fun activities.

Research

Research is one of our main priorities. We have set-up a research consortium to identify and encourage a collaborative approach across all disciplines and are pooling the knowledge and experience of Alström Syndrome and other rare diseases. We have begun a research project into the experiences of children in the early years.

We have continued to engage with the Canadian Pharmaceutical Company Prometic Bio Therapeutics Ltd as the first clinical trial for people affected by Alström Syndrome in the UK moved into phase 2.

We continued working in partnership with Rhythm Pharmaceuticals Inc. to provide practical support for patients with rare diseases, during a new clinical trial

Future Plans

We are ambitious and optimistic about the future. We aim to:

- Increase knowledge and understanding about Alstrom by improving the data we collect and disseminate, through the development and population of a patient registry
- Improve our understanding around diagnosis - Map the diagnostic journey and work with international partners to identify key factors and the touch points of diagnosis.
- Work with others to learn and understand more about the Alström Heart and the Alström Eye.
- Strengthen Governance
- Grow and develop the Breaking Down Barriers project to reach more organisations and develop good practice models to reach excluded communities.
- Continue to develop a personalised approach for individuals and Families affected by Alström Syndrome.

Alstrom Syndrome UK

Company Limited by Guarantee

Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 March 2019

Financial Review

The total surplus for the year amounted to £9,778 compared to a deficit of £46,425 last year.

Reserves Policy and Going Concern

The trustees review the level of reserves on a regular basis to ensure that the appropriate levels are maintained considering the main risks to the organisation and future developments. The following designated reserves are held at the year-end:

Financial Assistance Grant Fund £7,145 - Amount set aside to provide financial support to Alström patients and their families based upon an assessment of need.

Adult Empowerment Grant Fund £12,825 - Amount set aside to enable and empower adults with Alström to be used for a variety of activities that improve their ability to self-advocate, to meet up with other adults and try something new. Funds may also be used to improve communication and confidence for adults with Alström.

The remaining reserves of £85,093 are held in the General Fund. The trustees feel that the level of free reserves are justified.

The trustees hold restricted reserves of £70,865

The trustees have reviewed the circumstances of the Charity and consider that adequate resources continue to be available to fund its activities for the foreseeable future. The trustees are of the view that the charity is a going concern.

Management of Risk

The Trustees have identified that the main risks to the Charity are:

1. The NHS England clinic contract
2. The loss of key personnel
3. Failing to secure sufficient funds

The Trustees monitor the risks with contact and communication with the managers.

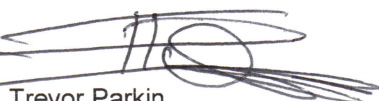
Small company provisions

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

Independent Examiner

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

The trustees' annual report was approved on 2nd November 19 and signed on behalf of the board of trustees by:



Trevor Parkin
Chair of Trustee

Alstrom Syndrome UK

Company Limited by Guarantee

Independent Examiner's Report to the Trustees of Alstrom Syndrome UK

Year ended 31 March 2019

I report to the trustees on my examination of the financial statements of Alstrom Syndrome UK ('the charity') for the year ended 31 March 2019.

Responsibilities and basis of report

As the trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

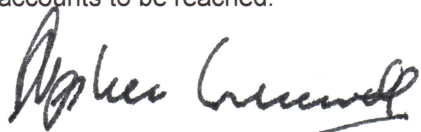
Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



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

2 November 2019

Alstrom Syndrome UK

Company Limited by Guarantee

Statement of Financial Activities (including income and expenditure account)

Year ended 31 March 2019

		Unrestricted funds	2019 Restricted funds	Total funds	2018 Total funds
	Note	£	£	£	£
Income and endowments					
Donations and legacies	5	2,953	1,917	4,870	4,906
Charitable activities	6	42,212	201,432	243,644	192,875
Investment income	7	764	–	764	242
Total income		<u>45,929</u>	<u>203,349</u>	<u>249,278</u>	<u>198,023</u>
Expenditure					
Expenditure on raising funds:					
Costs of raising donations and legacies	8	216	–	216	216
Expenditure on charitable activities	9,10	48,207	191,077	239,284	244,232
Total expenditure		<u>48,423</u>	<u>191,077</u>	<u>239,500</u>	<u>244,448</u>
Net income/(expenditure) and net movement in funds					
		<u>(2,494)</u>	<u>12,272</u>	<u>9,778</u>	<u>(46,425)</u>
Reconciliation of funds					
Total funds brought forward		107,557	58,593	166,150	212,575
Total funds carried forward		<u>105,063</u>	<u>70,865</u>	<u>175,928</u>	<u>166,150</u>

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

The notes on pages 11 to 21 form part of these financial statements.

Alstrom Syndrome UK
Company Limited by Guarantee
Statement of Financial Position

31 March 2019

	Note	2019 £	2018 £
Fixed assets			
Tangible fixed assets	16	2,778	4,098
Current assets			
Debtors	17	43,038	17,757
Investments	18	99,965	99,965
Cash at bank and in hand		43,341	81,321
		<u>186,344</u>	<u>199,043</u>
Creditors: amounts falling due within one year	19	13,194	36,991
Net current assets		<u>173,150</u>	<u>162,052</u>
Total assets less current liabilities		<u>175,928</u>	<u>166,150</u>
Net assets		<u>175,928</u>	<u>166,150</u>
Funds of the charity			
Restricted funds		70,865	58,593
Unrestricted funds		105,063	107,557
Total charity funds		<u>175,928</u>	<u>166,150</u>

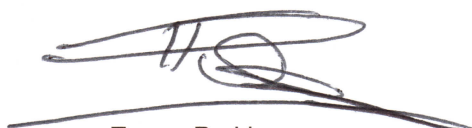
For the year ending 31 March 2019 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

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

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

2nd November 19... These financial statements were approved by the board of trustees and authorised for issue on ... and are signed on behalf of the board by:


Trevor Parkin
Chair of Trustee

The notes on pages 11 to 21 form part of these financial statements.

Alstrom Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements

Year ended 31 March 2019

1. General information

The charity is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is 4 St Kitts Close, Torquay, TQ2 7GD, Devon.

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Companies Act 2006.

3. Accounting policies

Basis of preparation

The financial statements have been prepared on the historical cost basis.

Going concern

There are no material uncertainties about the charity's ability to continue.

Disclosure exemptions

Under Charities SORP (FRS 102) the Charity is classed as a small charity and has therefore taken the exemption from the requirement to prepare a cashflow statement.

Judgements and key sources of estimation uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

Alstrom Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

3. Accounting policies *(continued)*

Incoming resources

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

Tangible assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses.

Alstrom Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

3. Accounting policies *(continued)*

Depreciation

Depreciation is calculated so as to write off the cost or valuation of an asset, less its residual value, over the useful economic life of that asset as follows:

Computer equipment - 25% straight line

Financial instruments

A financial asset or a financial liability is recognised only when the entity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs, unless the arrangement constitutes a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised as an expense in the period in which it arises.

4. Limited by guarantee

The Company is limited by guarantee, having no share capital. It is a registered charity. Under the provisions of Section 30 of the Companies Act 2006, the company is entitled to omit the word "Limited" from its name. In the event of the company being wound up, the liability of each member is limited to £10.

5. Donations and legacies

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Donations			
General Donations	<u>2,953</u>	<u>1,917</u>	<u>4,870</u>

Alstrom Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

5. Donations and legacies *(continued)*

	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £
Donations			
General Donations	<u>4,906</u>	<u>–</u>	<u>4,906</u>

6. Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Unrestricted	13,075	–	13,075
National Commissioning Grant	–	141,900	141,900
Transition Activities	–	16,600	16,600
Breaking Down Barriers	–	42,932	42,932
Family Support	–	–	–
Other income	29,137	–	29,137
	<u>42,212</u>	<u>201,432</u>	<u>243,644</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £
Unrestricted	4,000	–	4,000
National Commissioning Grant	–	133,585	133,585
Transition Activities	–	22,940	22,940
Breaking Down Barriers	–	20,000	20,000
Family Support	–	1,700	1,700
Other income	10,650	–	10,650
	<u>14,650</u>	<u>178,225</u>	<u>192,875</u>

7. Investment income

	Unrestricted Funds £	Total Funds 2019 £	Unrestricted Funds £	Total Funds 2018 £
Investment income	<u>764</u>	<u>764</u>	<u>242</u>	<u>242</u>

8. Costs of raising donations and legacies

	Unrestricted Funds £	Total Funds 2019 £	Unrestricted Funds £	Total Funds 2018 £
Fundraising Expenses	<u>216</u>	<u>216</u>	<u>216</u>	<u>216</u>

Alstrom Syndrome UK

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

9. Expenditure on charitable activities by fund type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
National Commissioning Grant	–	136,684	136,684
Transition Activities	–	15,530	15,530
Breaking Down Barriers	–	38,300	38,300
Financial Assistance Grant Fund	2,600	–	2,600
Adult Empowerment Grant Fund	2,975	–	2,975
General fund	–	–	–
Family Support	–	563	563
Support costs	42,632	–	42,632
	<u>48,207</u>	<u>191,077</u>	<u>239,284</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £
National Commissioning Grant	–	144,561	144,561
Transition Activities	–	25,106	25,106
Breaking Down Barriers	–	23,139	23,139
Financial Assistance Grant Fund	2,255	–	2,255
Adult Empowerment Grant Fund	1,200	–	1,200
General fund	4,494	–	4,494
Family Support	–	–	–
Support costs	43,477	–	43,477
	<u>51,426</u>	<u>192,806</u>	<u>244,232</u>

10. Expenditure on charitable activities by activity type

	Activities undertaken directly	Support costs	Total funds 2019 £	Total fund 2018 £
National Commissioning Grant	136,684	–	136,684	144,561
Transition Activities	15,530	–	15,530	25,106
Breaking Down Barriers	38,300	–	38,300	23,139
Financial Assistance Grant Fund	2,600	–	2,600	2,255
Adult Empowerment Grant Fund	2,975	–	2,975	1,200
Support costs	–	42,632	42,632	43,477
General fund	–	–	–	4,494
Family Support	563	–	563	–
	<u>196,652</u>	<u>42,632</u>	<u>239,284</u>	<u>244,232</u>

Alstrom Syndrome UK

Company Limited by Guarantee

Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

11. Analysis of support costs

	Support costs £	Total 2019 £	Total 2018 £
Staff costs	26,354	26,354	22,358
Membership fees	156	156	482
Sundry expenses	253	253	635
Telephone and Fax	303	303	399
Depreciation	408	408	408
Insurance	519	519	525
Conference fees	1,572	1,572	2,687
Accountancy fees	1,070	1,070	1,335
Professional fees	—	—	350
Contractors fees	8,625	8,625	7,375
Hotels, traveling and subsistence costs	6,617	6,617	4,305
Printing, postage, stationery and advertising	(3,245)	(3,245)	2,618
	<u>42,632</u>	<u>42,632</u>	<u>43,477</u>

12. Net income/(expenditure)

Net income/(expenditure) is stated after charging/(crediting):

	2019 £	2018 £
Depreciation of tangible fixed assets	<u>1,320</u>	<u>774</u>

13. Independent examination fees

	2019 £	2018 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>2,140</u>	<u>2,040</u>

14. Staff costs

The total staff costs and employee benefits for the reporting period are analysed as follows:

	2019 £	2018 £
Wages and salaries	146,758	128,884
Social security costs	10,331	9,093
Employer contributions to pension plans	6,538	5,707
Other employee benefits	1,790	1,084
	<u>165,417</u>	<u>144,768</u>

The average head count of employees during the year was 7 (2018: 5). The average number of full-time equivalent employees during the year is analysed as follows:

	2019 No.	2018 No.
Staff	<u>5</u>	<u>4</u>

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

14. Staff costs *(continued)*

No employee received employee benefits of more than £60,000 during the year (2018: Nil).

15. Trustee remuneration and expenses

No Trustee received remuneration during the year or the previous year. No Trustee or other person related to the Charity had any personal interest in any contract entered into by the Charity during the year.

During the year 6 (2018 5) Trustees claimed out of pocket expenses relating to travel and accommodation to attend Trustees meetings. These claims totalled £1,087 (2018 £1,155).

16. Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2018 and 31 March 2019	5,228
Depreciation	
At 1 April 2018	1,130
Charge for the year	1,320
At 31 March 2019	<u>2,450</u>
Carrying amount	
At 31 March 2019	<u>2,778</u>
At 31 March 2018	<u>4,098</u>

17. Debtors

	2019 £	2018 £
Prepayments and accrued income	<u>43,038</u>	<u>17,757</u>

18. Investments

	2019 £	2018 £
Deposits	<u>99,965</u>	<u>99,965</u>

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

19. Creditors: amounts falling due within one year

	2019	2018
	£	£
Accruals and deferred income	8,277	34,150
Social security and other taxes	4,917	2,841
	<u>13,194</u>	<u>36,991</u>

20. Pensions and other post retirement benefits

Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £6,538 (2018: £5,707).

21. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Tangible fixed assets	526	2,252	2,778
Current assets	109,122	77,222	186,344
Creditors less than 1 year	(4,585)	(8,609)	(13,194)
Net assets	<u>105,063</u>	<u>70,865</u>	<u>175,928</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £
Tangible fixed assets	934	3,164	4,098
Current assets	123,238	75,805	199,043
Creditors less than 1 year	(16,615)	(20,376)	(36,991)
Net assets	<u>107,557</u>	<u>58,593</u>	<u>166,150</u>

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

22. Analysis of charitable funds

Unrestricted funds - 2019

	At 1 April 2018 £	Income £	Expenditure £	Transfers £	At 31 March 2019 £
General Fund	82,012	45,929	(42,848)	–	85,093
Financial Assistance Grant Fund	9,745	–	(2,600)	–	7,145
Adult Empowerment Grant Fund	15,800	–	(2,975)	–	12,825
	<u>107,557</u>	<u>45,929</u>	<u>(48,423)</u>	<u>–</u>	<u>105,063</u>

Unrestricted funds - 2018

	At 1 April 2017 £	Income £	Expenditure £	Transfers £	At 31 March 2018 £
General Fund	110,401	19,798	(48,187)	–	82,012
Financial Assistance Grant Fund	12,000	–	(2,255)	–	9,745
Adult Empowerment Grant Fund	17,000	–	(1,200)	–	15,800
	<u>139,401</u>	<u>19,798</u>	<u>(51,642)</u>	<u>–</u>	<u>107,557</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 Alstrom patients and their families based upon an assessment of need.

Adult Empowerment Grant Fund

Amount set aside to enable and empower adults with Alstrom to be used for a variety of activities that improve their ability to self-advocate and to meet up with other adults. Funds may also be used to improve communication and confidence for adults with Alstrom.

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

Restricted funds - 2019

	At 1 April 2018 £	Incoming Resources £	Outgoing Resources £	Transfers £	At 31 March 2019 £
National Commissioning Grant	15,698	141,900	(136,684)	–	20,914
<u>Transition Activities</u>					
Children in Need	3,701	16,600	(15,530)	–	4,771
<u>Sylvia Adams Trust</u>					
Breaking Down Barriers	16,788	42,932	(38,300)	–	21,420
<u>Family Support</u>					
Smaller Restricted Funds	1,700	1,917	(563)	–	3,054
<u>Research and development</u>					
One in a million	20,706	–	–	–	20,706
	<u>58,593</u>	<u>203,349</u>	<u>(191,077)</u>	<u>–</u>	<u>70,865</u>

Restricted funds - 2018

	At 1 April 2017 £	Incoming Resources £	Outgoing Resources £	Transfers £	At 31 March 2018 £
National Commissioning Grant	26,674	133,585	(144,561)	–	15,698
<u>Transition Activities</u>					
Children in Need	5,867	22,940	(25,106)	–	3,701
<u>Sylvia Adams Trust</u>					
Breaking Down Barriers	19,927	20,000	(23,139)	–	16,788
<u>Family Support</u>					
Smaller Restricted Funds	–	1,700	–	–	1,700
<u>Research and development</u>					
One in a million	20,706	–	–	–	20,706
	<u>73,174</u>	<u>178,225</u>	<u>(192,806)</u>	<u>–</u>	<u>58,593</u>

Purpose 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 Alstrom patients and their families.

Breaking down Barriers

Funding to facilitate patient organisations and support groups to join together to share examples of good practice and develop new guidelines to highlight effective ways to support families.

Children in Need

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

One in a Million Fund

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

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Notes to the Financial Statements *(continued)*

Year ended 31 March 2019

23. Related party transactions

During the year there were no related party transactions (2018: None)