

REGISTERED COMPANY NUMBER: 04814120 (England and Wales)
REGISTERED CHARITY NUMBER: 1101052

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR THE
YEAR ENDED 30 JUNE 2019
FOR
THE ALKAPTONURIA SOCIETY LTD

Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

THE ALKAPTONURIA SOCIETY LTD

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FOR THE YEAR ENDED 30 JUNE 2019

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THE ALKAPTONURIA SOCIETY LTD

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 30 JUNE 2019

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 30 June 2019. The trustees have adopted the provisions of Accounting and Reporting by Charities: 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) (effective 1 January 2015).

About Alkaptonuria

AKU, also known as Black Bone Disease, is an extremely rare genetic condition, which can cause significant damage to the bones, cartilage and tissues. AKU usually affects one in every 250,000 people worldwide. It is a recessive condition that is caused by a mutation of one chromosome; this means that if two people carry the faulty gene, their child has a 25% chance of developing AKU.

AKU stops patients' bodies from breaking down a chemical called homogentisic acid (HGA) which the body naturally produces during the digestion of food. Due to this, HGA builds up in the body and, over time, leads to black and brittle bones and cartilage, and early-onset osteoarthritis. The build-up of HGA in the body can also lead to other, sometimes more severe health complications.

Founded in 2003, the AKU Society offers life-changing support to patients and their families. It provides patients with personalised care and home visits, along with the latest information from specialist workshops, our website, social media and online patient communities. The AKU Society also pioneers ground-breaking research into the disease, including a European-wide clinical trial into a drug called nitisinone and the exploration of new innovative therapies. We see a future where no one born with AKU anywhere in the world has the symptoms of this disease. Through patient support, community building and medical research, the AKU Society aims to transform the lives of AKU patients.

AKU patients, like all rare disease patients, feel isolated because of their disease. Many patients have had years of misdiagnosis and misunderstanding by the medical profession. Often, their family finds it hard to understand what is wrong. This leaves many AKU patients feeling depressed. The AKU Society changes this by bringing patients together. Projects such as Rare Connect (a European focused rare disease support forum), Patients Like Me (a US-led support forum and health assessment platform), Patients Know Best (an online medical record sharing system), and our biennial international and annual domestic patient workshops build a broader community. Our social media channels and newly redesigned website inform the public and medical professionals about our work and the advances in research into the disease. We target health care professionals through exhibitions and online e-learning modules to increase the profile of the disease and its perception.

The AKU Society actively encourages patients to share their experiences and impart the best methods to cope with this rare disease with each other and their wider community.

The most useful way we can help our patients is through active research into the understanding and treatment of AKU. Our goal is to find a cure for the disease. We continue to build strong partnerships with universities and hospitals to expand the scientific knowledge of AKU and its treatment.

THE ALKAPTONURIA SOCIETY LTD

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 30 JUNE 2019

OBJECTIVES AND ACTIVITIES

Objectives and aims

Transforming the lives of AKU Patients: through patient support, community building and medical research.

1. **Patient Support** - Through reliable information, workshops, events and hands-on support at the National Alkaptonuria Centre and the DevelopAKUre clinical trial programme.
Living with AKU is challenging, with loss of mobility and pain affecting patients' physical and mental health. Therefore, we provide support to our patients and their families, helping them come to terms with the diagnosis and best manage their condition
2. **Community Building** - uniting AKU patients in the UK and abroad and helping raise awareness of the disease among the public and medical professionals.
Living with a rare disease can be isolating, as patients are sparsely located all over the world. We work hard to unite AKU patients and build an active community.
3. **Medical Research** - to understand and treat the disease.
Our goal is to find a cure for this debilitating disease. We have successfully finished an international clinical trial, DevelopAKUre, measuring the effectiveness of nitisinone, the first potential treatment for AKU. We want this to be available to all AKU patients across the globe.

Achievements and performance during the period

The AKU Society continues to run three key projects.

1. **National Alkaptonuria Centre (NAC)**- Based at the Royal Liverpool and Broadgreen University Hospital and funded by the NHS Highly Specialised Services, the NAC continues to offer yearly checkups, expert care, monitoring and pain relief to patients based in Scotland and England along with access to the drug nitisinone off-label, meaning without a license. Welsh patients also have access to the centre dependent on funding from Welsh specialised services. The AKU Society supports the running of the NAC through patient liaison, logistics and ensuring patients are prepared for their annual clinic. We also continue to find new patients, manage referrals and fight for equity of access for all patients based in the UK.
2. **DevelopAKUre** - This was a series of three major international clinical trials into the efficacy of nitisinone as a treatment for AKU. In partnership with 12 other organisations made up of pharmaceutical, clinical and patient support organisations, the trials tested whether nitisinone is effective in reducing the acid that causes the damage in AKU. The AKU Society supported the trials, leading on patient recruitment, patient retention, management and dissemination. DevelopAKUre ended in January 2019 with positive results. We will continue to support the DevelopAKUre consortium as we move forward towards licensing of the drug in Europe and beyond.
3. **Breaking Down Barriers, Reaching Ethnic Minority Communities** - Funded by the Sylvia Adam's Trust and with support from rare disease patient group Alström UK, this project aims to target groups in the UK where English isn't the first language. Over the past three years, many referrals to the NAC have been from ethnic minority groups. This project aims to provide our information in a format accessible to these groups. We have translated our print leaflets and have installed an innovative plugin called Browsealoud onto our website that translates information into the user's chosen language, along with options for dictation and to increase font size for those with visual impairment. We have also begun a GP video campaign to be screened in GP surgeries across the country. The video is highly visual and accessible to anyone irrelevant of their language.

In April 2018 we held our 2nd international workshop, inviting patients from all over the world to hear about the latest research advances in Liverpool, the home of the NAC. Feedback from attendees was extremely positive.

Public benefit

The Trustees have complied with S17(5) of the Charities Act 2011 and have had due regard to the guidance on Public

Benefit by the Charity Commission when exercising relevant powers and duties. See "About Alkaptonuria" section for details of how the charity provides a public benefit.

THE ALKAPTONURIA SOCIETY LTD

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 30 JUNE 2019**

OBJECTIVES AND ACTIVITIES

Partnerships

The AKU Society works in close partnership with several organisations, most notably the University of Liverpool (with Prof Jim Gallagher and his lab at the Institute of Ageing and Chronic Disease), the Royal Liverpool and Broadgreen University Hospital Trust (with Prof L Ranganath at the Department of Clinical Chemistry) and Liverpool John Moores University (with Dr Gabor Barton at the Department of Sports and Exercise Science).

The AKU Society was founded in Liverpool, so our links there are the strongest. Liverpool is the home of the National AKU Centre, an NHS-funded clinical centre of excellence for the treatment of AKU.

FINANCIAL REVIEW

Principal funding sources

The charity's principal funding sources are grants from the European Commission and funding for the National AKU Centre from the Royal Liverpool University Hospital.

Investment policy and objectives

The Trustees have the power to invest any monies not immediately required for charitable purposes of the Company. The policy involves investing in ethical bonds.

Reserves policy

At any time, the Charity is to keep enough reserves to enable it to meet its contractual obligations for up to 12 months. Any excess reserves will be used to increase work to meet our charitable objectives.

Incoming resources for the year totalled £266,546 (2018: £227,021) of which £261,807 (2018: £214,870) related to funding for projects upon which restrictions are placed. Total expenditure for the period was £251,705 (2018: £213,597).

At 30 June 2019 the Charity's total funds stood at £440,064 (2018:£425,223) of which £256,218 (2018:£240,266) represented restricted funds. Details of each restricted fund are shown in the notes to the accounts.

FUTURE PLANS

The AKU Society is focusing on implementing a clinical study of children with AKU in order to find out at what age the damage caused by AKU starts. This will then give us an indication of when to start treating with nitisinone. This is a five-year study with the Royal Liverpool University Hospital and with partner hospitals in Manchester, Birmingham and London Great Ormond Street.

We are also starting to work on developing a gene therapy, which would ultimately be a cure for AKU. We are seeking funding to test out various strategies for gene therapy research in the AKU laboratories at the University of Liverpool.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The Alkaptonuria Society is a charitable company limited by guarantee governed by its Memorandum and Articles of Association dated 27th June 2003. It registered as a charity with the Charity Commission on 5th December 2003.

Recruitment and appointment of new trustees

As set out in the Articles of Association, at every Annual General Meeting one third of the Trustees shall be subject to retirement by rotation. Those who have been longest in office since their last appointment will be subject to this requirement. If the vacancy left by the retiring Trustee is not filled at the meeting, if willing to continue, the retiring Trustee will be reappointed.

Induction and training of new trustees

All Trustees receive a full induction and training day, in accordance with Charity Commission good practice. They are briefed on their legal obligations under charity and company law, the specific structure of Alkaptonuria Society as a Company Limited by Guarantee, including the committee and decision making process and business plan. During this training day they will meet key employees and co-trustees

THE ALKAPTONURIA SOCIETY LTD

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 30 JUNE 2019

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

04814120 (England and Wales)

Registered Charity number

1101052

Registered office

66 Devonshire Road
CAMBRIDGE
Cambridgeshire
CB1 2BL

Trustees

Prof L R Ranganath	Doctor
Prof A Shenkin	Emeritus Professor
Dr N T Sireau PhD	Charity CEO
W A Esmond	Retired
Dr D Batty	
Prof J A Gallagher	

Independent examiner

Matthew Pettifer FCA
Institute of Chartered Accountants in England and Wales
Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Solicitors

White & Case LLP, 5 Old Broad Street, LONDON, EC2N 1DW

Bankers

Co-operative Bank plc
PO Box 250
Delf House
SKELMERSDALE
WN8 6WT

Unity Trust Bank
Nine Brindley Place
BIRMINGHAM
B1 2HB

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the board of trustees on 22/11/2019 and signed on its behalf by:


.....
Dr N T Sireau PhD - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
THE ALKAPTONURIA SOCIETY LTD**

Independent examiner's report to the trustees of The Alkaptonuria Society Ltd ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2019.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts 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 your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of Institute of Chartered Accountants in England and Wales which is one of the listed bodies

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

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts 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 accounts 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



Matthew Pettifer FCA
Institute of Chartered Accountants in England and Wales
Staffords
Chartered Accountants
Unit 1, Cambridge House
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CAMBRIDGE
Cambridgeshire
CB3 0QH

Date: 22/1/19

THE ALKAPTONURIA SOCIETY LTD

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 30 JUNE 2019

	Notes	Unrestricted funds £	Restricted funds £	Total 2019 funds £	Total 2018 funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	3,235	-	3,235	9,995
Charitable activities	5				
Research		-	261,807	261,807	216,528
Investment income	4	954	-	954	498
Other income	6	550	-	550	-
Total		4,739	261,807	266,546	227,021
EXPENDITURE ON					
Raising funds	7	(29)	23,649	23,620	28,270
Charitable activities					
Research		6,834	221,251	228,085	185,327
Total		6,805	244,900	251,705	213,597
NET INCOME/(EXPENDITURE)		(2,066)	16,907	14,841	13,424
Transfers between funds	17	955	(955)	-	-
Net movement in funds		(1,111)	15,952	14,841	13,424
RECONCILIATION OF FUNDS					
Total funds brought forward		184,957	240,266	425,223	411,799
TOTAL FUNDS CARRIED FORWARD		183,846	256,218	440,064	425,223

The notes form part of these financial statements

THE ALKAPTONURIA SOCIETY LTD (REGISTERED NUMBER: 04814120)

BALANCE SHEET
AT 30 JUNE 2019

		Unrestricted funds	Restricted funds	Total	2019 funds	Total	2018 funds
	Not es	£	£		£		£
FIXED ASSETS							
Tangible assets	14	1,308	-		1,308		1,195
CURRENT ASSETS							
Debtors	15	-	96,146		96,146		120,483
Cash at bank		<u>182,563</u>	<u>166,101</u>		<u>348,664</u>		<u>307,335</u>
		182,563	262,247		444,810		427,818
CREDITORS							
Amounts falling due within one year	16	(25)	(6,029)		(6,054)		(3,790)
NET CURRENT ASSETS		<u>182,538</u>	<u>256,218</u>		<u>438,756</u>		<u>424,028</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>183,846</u>	<u>256,218</u>		<u>440,064</u>		<u>425,223</u>
NET ASSETS		<u>183,846</u>	<u>256,218</u>		<u>440,064</u>		<u>425,223</u>
FUNDS	17						
Unrestricted funds					183,846		184,957
Restricted funds					<u>256,218</u>		<u>240,266</u>
TOTAL FUNDS					<u>440,064</u>		<u>425,223</u>

The notes form part of these financial statements

THE ALKAPTONURIA SOCIETY LTD (REGISTERED NUMBER: 04914120)

BALANCE SHEET - CONTINUED
AT 30 JUNE 2019

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 June 2019.


The members have not required the company to obtain an audit of its financial statements for the year ended 30 June 2019 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

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

The financial statements were approved by the Board of Trustees on *22/6/2019* and were signed on its behalf by:


.....
Dr N T Sireau PhD-Trustee

The notes form part of these financial statements

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2019

1. LEGAL FORM

The charity is a registered charity registered in England and Wales number 1101052 and a company limited by guarantee, having no share capital, incorporated in England and Wales number 04814120.

Its registered office and principal place of business is 66 Devonshire Road, Cambridge, CB1 2BL.

The operations of the entity are to educate the public regarding Alkaptonuria Disease through an internet website; provide information and advice to sufferers via a National AKU Centre, hosting conferences and through online community projects; and to promote research into Alkaptonuria Disease by working with research teams in the Universities in Liverpool.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: 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) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The trustees consider there to be no material uncertainties about the charity's ability to continue as a going concern.

The charity is a public benefit entity.

Financial reporting standard 102 - reduced disclosure exemptions

The charity has taken advantage of the following disclosure exemption in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donations are recognised on receipt.

Grant income is recognised in full on receipt unless there are unfulfilled performance conditions that do not allow the income to be recognised. In this case the grant is accounted for as a liability until the performance conditions have been met.

Grant income is only deferred if the grant is time-related and relates partly or wholly to a post year-end time period.

The charity becomes entitled to the EC grant income once eligible expenditure is made, so income is accrued where expenditure has been incurred.

The charity is not VAT registered.

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

2. ACCOUNTING POLICIES - continued

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Raising funds

Raising funds includes all expenditure incurred by the charity to raise funds for its charitable purposes and includes costs of all fundraising activities, events and non-charitable trading.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Governance costs

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the examination fees and costs linked to the strategic management of the charity.

Allocation and apportionment of costs

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis, e.g estimated usage.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off the cost less estimated residual value of each asset over its estimated useful life.

Plant and machinery - 33% on cost and 25% on reducing balance

All assets costing more than £500 are capitalised.

Taxation

The charity is exempt from corporation tax on its charitable activities. Irrecoverable VAT is included in the cost of the expense to which it relates.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Research and development

Expenditure on research and development is written off in the year in which it is incurred.

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

2. ACCOUNTING POLICIES - continued

Pension costs and other post-retirement benefits

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening the deposit or similar account.

Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be estimated or measured reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised as transaction value and subsequently measured at their settlement value.

3. DONATIONS AND LEGACIES

	2019	2018
	£	£
Donations	<u>3,235</u>	<u>9,995</u>

4. INVESTMENT INCOME

	2019	2018
	£	£
Deposit account interest	<u>954</u>	<u>498</u>

5. INCOME FROM CHARITABLE ACTIVITIES

		2019	2018
	Activity	£	£
Grants	Research	<u>261,807</u>	<u>216,528</u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

5. INCOME FROM CHARITABLE ACTIVITIES - continued

Grants received, included in the above, are as follows:

	2019	2018
	£	£
Rosetree Trust	1,000	4,000
Childwick Trust	30,000	-
National AKU Centre	155,530	124,939
European Commission FP7 DevelopAKUre project	75,277	60,539
Sylvia Adams Charitable Trust	-	5,000
Swedish Orphan Biovitrum	-	13,300
Pilkingtons Charity Fund	-	7,000
James Roll Charitable Trust	-	1,000
Woodroffe Benton Foudnation	-	750
	<u>261,807</u>	<u>216,528</u>

6. OTHER INCOME

	2019	2018
	£	£
Other income	<u>550</u>	<u>-</u>

7. RAISING FUNDS

Raising donations and legacies

	2019	2018
	£	£
Costs of generating income	18,820	28,270
Website development	<u>4,800</u>	<u>-</u>
	<u>23,620</u>	<u>28,270</u>

8. GRANTS PAYABLE

	2019	2018
	£	£
Research	<u>10,000</u>	<u>12,500</u>

The total grants paid to institutions during the year was as follows:

	2019	2018
	£	£
Findacure	<u>10,000</u>	<u>-</u>

The total grants paid to individuals during the year was as follows:

	2019	2018
	£	£
Other grants	<u>-</u>	<u>12,500</u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

9. SUPPORT COSTS

	Governance costs £
Research	<u>5,508</u>

10. NET INCOME/(EXPENDITURE)

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

	2019 £	2018 £
Depreciation - owned assets	<u>842</u>	<u>676</u>

11. TRUSTEES' REMUNERATION AND BENEFITS

Dr N Sireau, a trustee, was remunerated for his services Chief Executive. Permission to pay this salary was received from the Charity Commission in accordance with Clause 5 of the Articles of Association.

	2019 £	2018 £
Trustees' salaries	42,917	-
Trustees' social security	3,738	-
Trustees' pension contributions	<u>2,145</u>	<u>-</u>
	<u>48,800</u>	<u>-</u>

Trustees' expenses

There were no trustees' expenses paid for the year ended 30 June 2019 nor for the year ended 30 June 2018.

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

12. STAFF COSTS

	2019	2018
	£	£
Wages and salaries	126,084	74,056
Social security costs	8,657	4,923
Other pension costs	<u>5,633</u>	<u>3,370</u>
	<u>140,374</u>	<u>82,349</u>

The staff costs relating to Key Management Personnel were £119,745 (2018: £56,255).

The average monthly number of employees during the year was as follows:

	2019	2018
Chief Executive Officer	1	-
Patient Support Manager	1	1
Communications Manager	1	1
Administrative assistant	-	1
Fundraising Officer	<u>1</u>	<u>-</u>
	<u>4</u>	<u>3</u>

No employees received emoluments in excess of £60,000.

13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
INCOME AND ENDOWMENTS FROM			
Donations and legacies	9,903	92	9,995
Charitable activities			
Research	1,750	214,778	216,528
Investment income	<u>498</u>	<u>-</u>	<u>498</u>
Total	12,151	214,870	227,021
 EXPENDITURE ON			
Raising funds	-	28,270	28,270
Charitable activities			
Research	<u>20,041</u>	<u>165,286</u>	<u>185,327</u>
Total	20,041	193,556	213,597
 NET INCOME/(EXPENDITURE)	(7,890)	21,314	13,424

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued	Unrestricted funds	Restricted funds	Total funds
	£	£	£
RECONCILIATION OF FUNDS			
Total funds brought forward	192,847	218,952	411,799
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS CARRIED FORWARD	<u>184,957</u>	<u>240,266</u>	<u>425,223</u>
14. TANGIBLE FIXED ASSETS			Plant and machinery
			£
COST			
At 1 July 2018			10,068
Additions			<u>955</u>
At 30 June 2019			<u>11,023</u>
DEPRECIATION			
At 1 July 2018			8,873
Charge for year			<u>842</u>
At 30 June 2019			<u>9,715</u>
NET BOOK VALUE			
At 30 June 2019			<u>1,308</u>
At 30 June 2018			<u>1,195</u>
15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR			
		2019	2018
		£	£
Prepayments and accrued income		<u>96,146</u>	<u>120,483</u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR - continued

Accrued income of £90,410 (2018: £85,062 from the European Commission Grant is included above as the income can only be recognised when the expenditure has been incurred.

Movement on accrued /(deferred income) in the year was as follows:

	2019	2018
Accrued / (Deferred income) as at 30 June 2018	85,062	24,522
EC Grant received in year	(69,929)	
Income recognised in year	75,277	60,540
Accrued income at 30 June 2019	90,410	85,062

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2019	2018
	£	£
Trade creditors	2,315	222
Other creditors	721	475
Accruals and deferred income	3,018	3,093
	6,054	3,790

17. MOVEMENT IN FUNDS

	At 1/7/18	Net movement in funds	Transfers between funds	At 30/6/19
	£	£	£	£
Unrestricted funds				
General Fund	183,655	(1,224)	-	182,431
Designated Fixed Asset Fund	1,195	(842)	955	1,308
Designated Royalties	107	-	-	107
	184,957	(2,066)	955	183,846
Restricted funds				
National AKU Centre	213,995	(685)	(955)	212,355
Childwick Trust	-	28,613	-	28,613
London Catalyst	2,000	(2,000)	-	-
Breaking Down Barriers	6,052	(661)	-	5,391
Children's Workshop	121	-	(121)	-
SOBI	4,066	(3,360)	(288)	418
Ethnic Minorities Project	5,000	(5,000)	-	-
Bedfordshire Support and Social Fund	2,032	-	-	2,032
Tyrosine Degradation Study	7,000	-	-	7,000
Patient Workshop	-	-	409	409
	240,266	16,907	(955)	256,218
TOTAL FUNDS	425,223	14,841	-	440,064

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

17. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Fund	4,739	(5,963)	(1,224)
Designated Fixed Asset Fund	-	(842)	(842)
	<u>4,739</u>	<u>(6,805)</u>	<u>(2,066)</u>
Restricted funds			
National AKU Centre	155,530	(156,215)	(685)
Childwick Trust	30,000	(1,387)	28,613
European Commission - FP7 DevelopAKUre project	75,277	(75,277)	-
Rosetrees	1,000	(1,000)	-
Breaking Down Barriers	-	(661)	(661)
SOBI	-	(3,360)	(3,360)
London Catalyst	-	(2,000)	(2,000)
Ethnic Minorities Project	-	(5,000)	(5,000)
	<u>261,807</u>	<u>(244,900)</u>	<u>16,907</u>
TOTAL FUNDS	<u>266,546</u>	<u>(251,705)</u>	<u>14,841</u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

17. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/7/17	Net movement in funds	Transfers between funds	At 30/6/18
	£	£	£	£
Unrestricted Funds				
General Fund	192,213	(7,215)	(1,344)	183,654
Designated Fixed Asset Fund	526	(675)	1,344	1,195
Designated Royalties	<u>108</u>	<u>-</u>	<u>-</u>	<u>108</u>
	192,847	(7,890)	-	184,957
Restricted Funds				
National AKU Centre	164,844	49,151	-	213,995
Big Lottery Fund - Online AKU Project	33,089	(33,089)	-	-
London Catalyst	2,000	-	-	2,000
Breaking Down Barriers	5,000	1,052	-	6,052
Autumn Patient Workshop	5,000	(5,000)	-	-
Children's Workshop	1,079	(958)	-	121
SOBI	908	3,158	-	4,066
Ethnic Minorities Project	5,000	-	-	5,000
Bedfordshire Support and Social Fund	2,032	-	-	2,032
Tyrosine Degradation Study	<u>-</u>	<u>7,000</u>	<u>-</u>	<u>7,000</u>
	218,952	21,314	-	240,266
TOTAL FUNDS	<u>411,799</u>	<u>13,424</u>	<u>-</u>	<u>425,223</u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

17. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Fund	12,151	(19,366)	(7,215)
Designated Fixed Asset Fund	-	(675)	(675)
	<u>12,151</u>	<u>(20,041)</u>	<u>(7,890)</u>
Restricted funds			
National AKU Centre	125,031	(75,880)	49,151
Big Lottery Fund - Online AKU Project	-	(33,089)	(33,089)
European Commission - FP7 DevelopAKUre project	60,539	(60,539)	-
Rosetrees	4,000	(4,000)	-
Breaking Down Barriers	5,000	(3,948)	1,052
Autumn Patient Workshop	-	(5,000)	(5,000)
Children's Workshop	-	(958)	(958)
SOBI	13,300	(10,142)	3,158
Tyrosine Degradation Study	7,000	-	7,000
	<u>214,870</u>	<u>(193,556)</u>	<u>21,314</u>
TOTAL FUNDS	<u>227,021</u>	<u>(213,597)</u>	<u>13,424</u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

17. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/7/17 £	Net movement in funds £	Transfers between funds £	At 30/6/19 £
Unrestricted funds				
General Fund	192,213	(8,439)	(1,344)	182,430
Designated Fixed Asset Fund	526	(1,517)	2,299	1,308
Designated Royalties	108	-	-	108
Restricted funds				
National AKU Centre	164,844	48,466	(955)	212,355
Big Lottery Fund - Online AKU Project	33,089	(33,089)	-	-
Childwick Trust	-	28,613	-	28,613
London Catalyst	2,000	(2,000)	-	-
Breaking Down Barriers	5,000	391	-	5,391
Autumn Patient Workshop	5,000	(5,000)	-	-
Children's Workshop	1,079	(958)	(121)	-
SOBI	908	(202)	(288)	418
Ethnic Minorities Project	5,000	(5,000)	-	-
Bedfordshire Support and Social Fund	2,032	-	-	2,032
Tyrosine Degradation Study	-	7,000	-	7,000
Patient Workshop	-	-	409	409
	<u>218,952</u>	<u>38,221</u>	<u>(955)</u>	<u>256,218</u>
TOTAL FUNDS	<u>411,799</u>	<u>28,265</u>	<u>-</u>	<u>440,064</u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

17. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Fund	16,890	(25,329)	(8,439)
Designated Fixed Asset Fund	-	(1,517)	(1,517)
	<hr/>	<hr/>	<hr/>
	16,890	(26,846)	(9,956)
Restricted funds			
National AKU Centre	280,561	(232,095)	48,466
Childwick Trust	30,000	(1,387)	28,613
European Commission - FP7 DevelopAKUre project	135,816	(135,816)	-
Rosetrees	5,000	(5,000)	-
Breaking Down Barriers	5,000	(4,609)	391
SOBI	13,300	(13,502)	(202)
Tyrosine Degradation Study	7,000	-	7,000
Big Lottery Fund - Online AKU Project	-	(33,089)	(33,089)
London Catalyst	-	(2,000)	(2,000)
Autumn Patient Workshop	-	(5,000)	(5,000)
Children's Workshop	-	(958)	(958)
Ethnic Minorities Project	-	(5,000)	(5,000)
	<hr/>	<hr/>	<hr/>
	476,677	(438,456)	38,221
TOTAL FUNDS	<hr/> 493,567	<hr/> (465,302)	<hr/> 28,265

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

17. MOVEMENT IN FUNDS - continued

Bedfordshire Support and Social Fund

Funding from the Wixamtree Trust supporting AKU patients in Bedfordshire.

Breaking Down Barriers

Donations from the Sylvia Adams Charitable Trust towards work identified in the "Breaking Down Barriers" action plan. This includes funding Browsealoud, AKU Video and work in the community to raise awareness of AKU amongst ethnic minority groups.

Children's Workshop

Supporting children affected by AKU by holding a workshop at London Zoo in July 2017. This was funded by grants from Hospital Saturday Fund, the Headley Foundation and other donations.

Ethnic Minorities Project

Grant from Strangward Charitable Trust towards reaching communities project focusing on patients from ethnic minorities.

European Commission - FP7 DevelopAKUre project

This is a 66 month (5.5 year) project - extended to 75 months - that started on 1 November 2012. It is for a series of clinical trials for nitisinone, a very promising treatment for AKU. The project includes 13 partner organisations from seven EU countries. The lead coordinator is the Royal Liverpool University Hospital, which receives all the funds from the EC and then disburses them to the partner organisations.

National AKU Centre

Funding from the Royal Liverpool University Hospital for the Robert Gregory National AKU Centre.

London Catalyst

Continuing the work done for the online AKU community project.

SOBI

This is made up of various grants from Swedish Orphan Biovitrum AB. At the year end the remaining balance was part of a grant to cover the production costs of 100 copies of a patient information booklet for children,

Rosetrees

A 3 year research project, starting in June 2015, investigating protrusions, excrescences and adipocytes led by Professor Gallagher and Dr Adam Taylor.

Patient Workshop

This is made up of the balances of previous grants which, with agreement of the funders, have been reallocated to spend on the November 2019 patient workshop.

Tyrosine Degradation Study

Funding from Pilkintons Charitable Trust and the Hamamelius Trust towards the costs of research into Tyrosine Degradation.

Childwick Trust

Funding from the Childwick Trust into research to understand the evolution of AKU and document the extent of disease in under 16s, with a particular emphasis on studying the existence of ochronosis.

Designated Fixed Asset Fund

Fund designated to cover the remaining value of the fixed assets.

Designated Royalties

Royalties from the sale of a book edited by Dr N Sireau, which were distributed to each contributor to donate to a charity of their choice.

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 30 JUNE 2019

17. MOVEMENT IN FUNDS - continued

Transfers between funds

A transfer of £955 was made from NAC to the Designated Fixed Asset fund which was the cost of fixed assets purchased in the year.

In agreement with the funders, the balance of the Childrens Workshop project of £121 was transferred to Patient Workshop to be spent on the November workshop.

In agreement with the funders, the balance of the SOBI international workshop project of £288 was transferred to Patient Workshop to be spent on the November workshop.

18. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 30 June 2019.

19. INDEPENDENT EXAMINERS' REMUNERATION

	2019 £	2018 £
Fees relating to independent examination	3,012	2,772
Other services provided	<u>1,260</u>	<u>-</u>
	<u><u>4,272</u></u>	<u><u>2,772</u></u>