

**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 2020**  
**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 2020**

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## THE ALKAPTONURIA SOCIETY LTD

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 30 JUNE 2020**

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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 2020. 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 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 up-to-date and reliable information, annual UK patients' workshops and biennial international workshops, along with hands-on support at the National Alkaptonuria Centre (NAC).

Living with AKU is challenging, with loss of mobility and pain affecting patients' physical and mental health. This is why the support we provide to our patients and their families is vital. We help them come to terms with the diagnosis and give them the tools to best manage their condition.

2. Community Building - Uniting patients in the UK and abroad and helping raise awareness of the disease among the public and medical professionals.

Living with AKU is isolating. Patients are sparsely located all over the world, without access to care and doctors who know about their condition. We work hard to unite AKU patients and build an active community.

3. Medical Research - to understand, treat and cure AKU.

Our goal is finding a cure for AKU. We are at the end of a series of major internal clinical trials called DevelopAKUre, measuring the effectiveness and safety of the drug nitisinone to treat AKU. At the start of the year we found out this was successful, meaning we now, for the first time, can offer a disease modifying treatment for AKU across Europe. We are now championing research into other therapies and co-therapies to reach our goal of curing AKU.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**OBJECTIVES AND ACTIVITIES**

**Achievements and performance during the period**

**About Alkaptonuria**

AKU, also known as Black Bone Disease, is an extremely rare genetic condition, which causes 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 new 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, which finished earlier this year, and the exploration of future 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 encourages patients to share their experiences and impart the best methods to cope with this rare disease.

The most useful way we can help our patients is through 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.

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. COVID-19 has changed the way the AKU Society assists the NAC, with in person visits cancelled. We have supported patients through this difficult time with individual telephone calls and support and working with the NAC to ensure that they are ready to welcome patients back when it is appropriate.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**OBJECTIVES AND ACTIVITIES**

2. Develop AKUre and beyond

Develop AKUre 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. Earlier in 2019 we were informed that the last trial, SONIA 2, had shown that the drug is successful in lowering the amount of HGA in the body by 99.7%. SOBI, the company that makes the drug, has submitted nitisinone to the European Medicines Agency (EMA) for a licence to treat AKU. This will be the first effective treatment for AKU ever.

After the end of the trials we assisted all partners pursuing licensing and ensuring equity of access. Alongside nitisinone, we are continually researching and working with academia and industry to develop future treatments for AKU including combatting the side effects of nitisinone and a gene therapy which will hopefully cure AKU once and for all.

3. Mental Health Support & Breaking Down Barriers

Founded by the Sylvia Adams Trust and with support from another rare disease patient group Alstrom Syndrome UK, the Breaking Down Barriers project works towards improving equity of access to health services with a focus on families with genetic conditions who experience barriers to accessing mainstream services. This is third year of funding from Breaking Down Barriers. Previously, we were focused on increasing our interactions with ethnic minority communities; now, thanks to continued funding from the project, we are beginning to offer genetic testing and counseling to family members of AKU patients, concentrating on those from ethnic minority communities.

Patients with AKU are at an increased risk of mental health issues due to isolation, lack of social interactions and risk of unemployment. Due to this, and with feedback from patients, we have begun to formalise the mental health support we offer by planning on giving patients the opportunity to take part in telephone counseling. Initially offering six sessions, we will partner with qualified practitioners who will decide how the patient has progressed over the course of the therapy. We have begun to gather funding and expect to be able to offer this support very soon.

**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.

**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.

## **THE ALKAPTONURIA SOCIETY LTD**

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 30 JUNE 2020**

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#### **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 £312,800 (2019: £266,546) of which £275,006 (2019: £261,807) related to funding for projects upon which restrictions are placed. Total expenditure for the period was £246,952 (2019: £251,705).

At 30 June 2020 the Charity's total funds stood at £505,912 (2019: £440,064) of which £282,197 (2019: £256,218) represented restricted funds. Details of each restricted fund are shown in the notes to the accounts.

#### **FUTURE PLANS**

Nitisinone has side effects caused by an increase in the amino acid tyrosine. That's why we've started a programme of research into a plant enzyme that could break down tyrosine in the gut and avoid the side effects.

We're also working on a complete cure. Gene therapy is the ultimate way forward for genetic disorders such as AKU. If done correctly, it can repair the faulty gene and restore a normal metabolism for AKU patients. In 2019 we started working on funding applications to test gene therapy in our lab models at the University of Liverpool. We're still working on this and hope to secure funding later in 2020.

COVID has caused havoc around the globe and has of course affected our AKU work. AKU patients are reporting an increased sense of isolation, so we have put together a programme called 'Body to Mind' to help with this. We have applied to the Big Lottery Fund for funding to implement this.

Our research has also slowed down because the laboratories at the University of Liverpool were closed for six months from March to August apart from those working on COVID projects. So the AKU mouse model work and testing of the plant enzyme mentioned above had to be put on hold.

Nevertheless, the AKU Society remains in a good financial position and is continuing its work to support AKU patients, while the team at the University of Liverpool are starting to reopen the labs and move ahead with research. The National AKU Centre at the Royal Liverpool University Hospital was also closed for six months and reopened in September.

The COVID pandemic is set to continue for a while, but we believe we have the funding and resources in place to weather the storm.

#### **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.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**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

**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

**THE ALKAPTONURIA SOCIETY LTD**

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**REFERENCE AND ADMINISTRATIVE DETAILS**

**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 20 October 2020 and signed on its behalf by:

Dr N T Sireau PhD - Trustee



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

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**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 2020.

**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 REPORT TO THE TRUSTEES OF  
THE ALKAPTONURIA SOCIETY LTD**

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**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  
Camboro Business Park  
Oakington Road, Girton  
CAMBRIDGE  
Cambridgeshire  
CB3 0QH

Date: .....

**THE ALKAPTONURIA SOCIETY LTD**

**STATEMENT OF FINANCIAL ACTIVITIES**  
**(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)**  
**FOR THE YEAR ENDED 30 JUNE 2020**

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	3	32,105	10,000	42,105	3,235
<b>Charitable activities</b>					
Research	5	4,750	265,006	269,756	261,807
Investment income	4	939	-	939	954
Other income	6	-	-	-	550
<b>Total</b>		<b>37,794</b>	<b>275,006</b>	<b>312,800</b>	<b>266,546</b>
<b>EXPENDITURE ON</b>					
Raising funds	7	-	28,099	28,099	23,620
<b>Charitable activities</b>					
Research		2,889	215,964	218,853	228,085
<b>Total</b>		<b>2,889</b>	<b>244,063</b>	<b>246,952</b>	<b>251,705</b>
<b>NET INCOME</b>		<b>34,905</b>	<b>30,943</b>	<b>65,848</b>	<b>14,841</b>
Transfers between funds	17	4,964	(4,964)	-	-
<b>Net movement in funds</b>		<b>39,869</b>	<b>25,979</b>	<b>65,848</b>	<b>14,841</b>
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<b>183,846</b>	<b>256,218</b>	<b>440,064</b>	<b>425,223</b>
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>223,715</b>	<b>282,197</b>	<b>505,912</b>	<b>440,064</b>

The notes form part of these financial statements

**THE ALKAPTONURIA SOCIETY LTD (REGISTERED NUMBER: 04814120)**

**BALANCE SHEET**  
**30 JUNE 2020**

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
<b>FIXED ASSETS</b>					
Tangible assets	14	3,880	-	3,880	1,308
<b>CURRENT ASSETS</b>					
Debtors	15	-	10,355	10,355	96,146
Cash at bank		219,888	275,814	495,702	348,664
		<u>219,888</u>	<u>286,169</u>	<u>506,057</u>	<u>444,810</u>
<b>CREDITORS</b>					
Amounts falling due within one year	16	(53)	(3,972)	(4,025)	(6,054)
		<u>219,835</u>	<u>282,197</u>	<u>502,032</u>	<u>438,756</u>
<b>NET CURRENT ASSETS</b>					
		<u>223,715</u>	<u>282,197</u>	<u>505,912</u>	<u>440,064</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>					
		<u>223,715</u>	<u>282,197</u>	<u>505,912</u>	<u>440,064</u>
<b>NET ASSETS</b>					
		<u>223,715</u>	<u>282,197</u>	<u>505,912</u>	<u>440,064</u>
<b>FUNDS</b>					
Unrestricted funds:	17				
General Fund				69,728	182,431
Designated Fixed Asset Fund				3,880	1,308
Designated Royalties				107	107
Designated Research Fund				150,000	-
				<u>223,715</u>	<u>183,846</u>
Restricted funds				<u>282,197</u>	<u>256,218</u>
<b>TOTAL FUNDS</b>					
				<u>505,912</u>	<u>440,064</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 June 2020.

The members have not required the company to obtain an audit of its financial statements for the year ended 30 June 2020 in accordance with Section 476 of the Companies Act 2006.

The notes form part of these financial statements

**BALANCE SHEET - continued**

**30 JUNE 2020**

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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 and authorised for issue on 20 October 2020 and were signed on its behalf by:

N T Sireau PhD - Trustee

## **THE ALKAPTONURIA SOCIETY LTD**

### **NOTES TO THE FINANCIAL STATEMENTS** **FOR THE YEAR ENDED 30 JUNE 2020**

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#### **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 2019)', 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 charitable company has taken advantage of the following disclosure exemptions 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.

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**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**

Costs of generating funds comprise costs incurred in order to encourage others to donate to the charity and the costs associated with preparing bids and tenders for grant funding.

**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 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.

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**2. ACCOUNTING POLICIES - continued**

**Fund accounting**

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.

**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**

	<b>2020</b>	2019
	<b>£</b>	£
Donations	<b><u>42,105</u></b>	<u>3,235</u>



**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

**4. INVESTMENT INCOME**

	<b>2020</b>	2019
	£	£
Deposit account interest	<b>939</b>	954
	<u>          </u>	<u>          </u>

**5. INCOME FROM CHARITABLE ACTIVITIES**

	<b>2020</b>	2019
	£	£
Grants	<b>269,756</b>	261,807
	<u>          </u>	<u>          </u>

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

	<b>2020</b>	2019
	£	£
Rosetree Trust	-	1,000
Childwick Trust	<b>15,000</b>	30,000
National AKU Centre	<b>174,490</b>	155,530
European Commission FP7 DevelopAKUre project	<b>52,316</b>	75,277
Sylvia Adams Charitable Trust	<b>5,000</b>	-
Hospital Saturday Fund	<b>2,000</b>	-
Swedish Orphan Biovitrum	<b>1,200</b>	-
Cycle Pharmaceuticals	<b>5,000</b>	-
Awards for All	<b>10,000</b>	-
COVID support	<b>4,750</b>	-
	<u>          </u>	<u>          </u>
	<b>269,756</b>	261,807
	<u>          </u>	<u>          </u>

**6. OTHER INCOME**

	<b>2020</b>	2019
	£	£
Other income	-	550
	<u>          </u>	<u>          </u>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**7. RAISING FUNDS**

**Raising donations and legacies**

	<b>2020</b>	2019
	£	£
Costs of generating income	<b>28,099</b>	18,820
Website development	-	4,800
	<u><b>28,099</b></u>	<u>23,620</u>

**8. GRANTS PAYABLE**

	<b>2020</b>	2019
	£	£
Research	-	10,000
	<u>-</u>	<u>10,000</u>

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

	<b>2020</b>	2019
	£	£
Findacure	-	10,000
	<u>-</u>	<u>10,000</u>

**9. SUPPORT COSTS**

	Governance costs £
Research	<u><b>4,428</b></u>

**10. NET INCOME/(EXPENDITURE)**

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

	<b>2020</b>	2019
	£	£
Depreciation - owned assets	<u><b>2,392</b></u>	<u>842</u>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**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.

	<b>2020</b>	2019
	<b>£</b>	£
Trustees' salaries	<b>35,875</b>	42,917
Trustees' social security	<b>3,758</b>	3,738
Trustees' pension contributions	<b>1,794</b>	2,145
	<b><u>41,426</u></b>	<u>48,800</u>

**Trustees' expenses**

There were no trustees' expenses paid for the year ended 30 June 2020 nor for the year ended 30 June 2019.

**12. STAFF COSTS**

	<b>2020</b>	2019
	<b>£</b>	£
Wages and salaries	<b>122,035</b>	126,084
Social security costs	<b>8,814</b>	8,657
Other pension costs	<b>6,102</b>	5,633
	<b><u>136,951</u></b>	<u>140,374</u>

The staff costs relating to Key Management Personnel were £110,654 (2019: £119,745).

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

	<b>2020</b>	2019
Chief Executive Officer	<b>1</b>	1
Head of Projects	<b>1</b>	-
Patient Support Manager	<b>1</b>	1
Communications Manager	<b>-</b>	1
Fundraising Officer	<b>1</b>	1
	<b><u>4</u></b>	<u>4</u>

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

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

**13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	3,235	-	3,235
<b>Charitable activities</b>			
Research	-	261,807	261,807
Investment income	954	-	954
Other income	550	-	550
<b>Total</b>	<u>4,739</u>	<u>261,807</u>	<u>266,546</u>
<b>EXPENDITURE ON</b>			
Raising funds	(29)	23,649	23,620
<b>Charitable activities</b>			
Research	6,834	221,251	228,085
<b>Total</b>	<u>6,805</u>	<u>244,900</u>	<u>251,705</u>
<b>NET INCOME/(EXPENDITURE)</b>	<u>(2,066)</u>	<u>16,907</u>	<u>14,841</u>
<b>Transfers between funds</b>	<u>955</u>	<u>(955)</u>	<u>-</u>
<b>Net movement in funds</b>	(1,111)	15,952	14,841
<b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>	184,957	240,266	425,223
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u><u>183,846</u></u>	<u><u>256,218</u></u>	<u><u>440,064</u></u>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

**14. TANGIBLE FIXED ASSETS**

	Plant and machinery £
<b>COST</b>	
At 1 July 2019	11,023
Additions	4,964
	15,987
At 30 June 2020	15,987
 <b>DEPRECIATION</b>	
At 1 July 2019	9,715
Charge for year	2,392
	12,107
At 30 June 2020	12,107
 <b>NET BOOK VALUE</b>	
At 30 June 2020	3,880
	3,880
At 30 June 2019	1,308
	1,308

**15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2020	2019
	£	£
Prepayments and accrued income	10,355	96,146
	10,355	96,146

Accrued income of £nil (2019: £90,410 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:

	2020	2019
Accrued / (Deferred income) as at 30 June 2019	90,410	85,062
EC Grant received in year	(142,726)	(69,929)
Income recognised in year	52,316	75,277
	-	90,410
Accrued income at 30 June 2020	-	90,410

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

**16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2020	2019
	£	£
Trade creditors	155	2,315
Other creditors	769	721
Accruals and deferred income	3,101	3,018
	4,025	6,054
	4,025	6,054

**17. MOVEMENT IN FUNDS**

	At 1/7/19	Net movement in funds	Transfers between funds	At 30/6/20
	£	£	£	£
<b>Unrestricted funds</b>				
General Fund	182,431	37,297	(150,000 )	69,728
Designated Fixed Asset Fund	1,308	(2,392)	4,964	3,880
Designated Royalties	107	-	-	107
Designated Research Fund	-	-	150,000	150,000
	183,846	34,905	4,964	223,715
<b>Restricted funds</b>				
National AKU Centre	212,355	(17,257)	(4,964)	190,134
Childwick Trust	28,613	15,000	-	43,613
Breaking Down Barriers	5,391	5,000	-	10,391
SOBI	418	1,200	-	1,618
Bedfordshire Support and Social Fund	2,032	-	-	2,032
Tyrosine Degradation Study	7,000	-	-	7,000
Patient Workshop	409	17,000	-	17,409
SOFIA-Paediatric Study	-	10,000	-	10,000
	256,218	30,943	(4,964)	282,197
<b>TOTAL FUNDS</b>	440,064	65,848	-	505,912

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**17. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General Fund	37,794	(497)	37,297
Designated Fixed Asset Fund	-	(2,392)	(2,392)
	<u>37,794</u>	<u>(2,889)</u>	<u>34,905</u>
<b>Restricted funds</b>			
National AKU Centre	174,490	(191,747)	(17,257)
Childwick Trust	15,000	-	15,000
European Commission - FP7			
DevelopAKUre project	52,316	(52,316)	-
Breaking Down Barriers	5,000	-	5,000
SOBI	1,200	-	1,200
Patient Workshop	17,000	-	17,000
SOFIA-Paediatric Study	10,000	-	10,000
	<u>275,006</u>	<u>(244,063)</u>	<u>30,943</u>
<b>TOTAL FUNDS</b>	<u><u>312,800</u></u>	<u><u>(246,952)</u></u>	<u><u>65,848</u></u>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

**17. MOVEMENT IN FUNDS - continued**

**Comparatives for movement in funds**

	At 1/7/18 £	Net movement in funds £	Transfers between funds £	At 30/6/19 £
<b>Unrestricted funds</b>				
General Fund	183,655	(1,224)	-	182,431
Designated Fixed Asset Fund	1,195	(842)	955	1,308
Designated Royalties	107	-	-	107
	<u>184,957</u>	<u>(2,066)</u>	<u>955</u>	<u>183,846</u>
<b>Restricted funds</b>				
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
	<u>240,266</u>	<u>16,907</u>	<u>(955)</u>	<u>256,218</u>
<b>TOTAL FUNDS</b>	<u><u>425,223</u></u>	<u><u>14,841</u></u>	<u><u>-</u></u>	<u><u>440,064</u></u>



**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

**17. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
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>
<b>Restricted funds</b>			
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)	-
London Catalyst	-	(2,000)	(2,000)
Breaking Down Barriers	-	(661)	(661)
SOBI	-	(3,360)	(3,360)
Ethnic Minorities Project	-	(5,000)	(5,000)
	<u>261,807</u>	<u>(244,900)</u>	<u>16,907</u>
<b>TOTAL FUNDS</b>	<u><u>266,546</u></u>	<u><u>(251,705)</u></u>	<u><u>14,841</u></u>

**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.

**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.

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**17. MOVEMENT IN FUNDS - continued**

**SOBI**

This is made up of various grants from Swedish Orphan Biovitrium 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,

**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.

**SOFIA Paediatric Study**

Donation from Trysil Charitable Trust towards a Paediatric Study.

**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.

**Designated Research**

This comprises funds set aside by the Trustees for the research programme at the University of Liverpool.

**Transfers between funds**

£4,964 was transferred from the NAC fund to the designated fixed asset funds, representing fixed assets purchased in the year.

£200,000 was transferred from the General fund to the designated research fund, representing funds set aside by the Trustees for the research programme at the University of Liverpool.

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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**18. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 30 June 2020.

**19. INDEPENDENT EXAMINERS' REMUNERATION**

	<b>2020</b>	2019
	<b>£</b>	£
Fees relating to independent examination	3,024	3,012
Other services provided	-	1,260
	<u>3,024</u>	<u>4,272</u>
	<u><u>3,024</u></u>	<u><u>4,272</u></u>

**THE ALKAPTONURIA SOCIETY LTD**

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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	2020	2019
	£	£
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations	<b>42,105</b>	3,235
<b>Investment income</b>		
Deposit account interest	<b>939</b>	954
<b>Charitable activities</b>		
Grants	<b>269,756</b>	261,807
<b>Other income</b>		
Other income	-	550
<b>Total incoming resources</b>	<b>312,800</b>	266,546
 <b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Costs of generating income	<b>28,099</b>	18,820
Website development	-	4,800
	<b>28,099</b>	23,620
 <b>Charitable activities</b>		
Wages	<b>122,035</b>	126,084
Social security	<b>8,814</b>	8,657
Pensions	<b>6,102</b>	5,633
Research	<b>48,000</b>	3,000
Office costs	<b>17,404</b>	18,266
Travel & accommodation	<b>359</b>	33,678
Other	<b>9,319</b>	16,407
Donations	-	10
Plant and machinery	<b>2,392</b>	842
Grants to institutions	-	10,000
	<b>214,425</b>	222,577
 <b>Support costs</b>		
<b>Governance costs</b>		
Bookeeping and payroll costs	<b>1,403</b>	1,236
Carried forward	<b>1,403</b>	1,236

This page does not form part of the statutory financial statements

**THE ALKAPTONURIA SOCIETY LTD**

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 30 JUNE 2020**

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	2020	2019
	£	£
<b>Governance costs</b>		
Brought forward	<b>1,403</b>	1,236
Independent Examiners' fee	<b>3,025</b>	4,272
	<b>4,428</b>	5,508
Total resources expended	<b>246,952</b>	251,705
<b>Net income</b>	<b>65,848</b>	14,841

This page does not form part of the statutory financial statements