

**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 2024  
FOR  
THE ALKAPTONURIA SOCIETY LTD

Archangel Accounting  
Burnham House  
Splash Lane  
Wyton  
Huntingdon  
PE28 7AF

THE ALKAPTONURIA SOCIETY LTD

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FOR THE YEAR ENDED 30 JUNE 2024

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THE ALKAPTONURIA SOCIETY LTD

REPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 30 JUNE 2024

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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 2024. 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).

## THE ALKAPTONURIA SOCIETY LTD

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 30 JUNE 2024

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#### **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 patient workshops, biennial international workshops, hands-on support at the National Alkaptonuria Centre (NAC), individual home visits, and mental health support.

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 their diagnosis and provide them with the tools to best manage their condition.

##### 2. Community Building

Uniting patients in the UK and abroad and helping to raise awareness of the disease among the public and medical professionals.

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

##### 3. Medical Research

To understand, treat, and cure AKU.

Our ultimate goal is finding a cure for AKU. We now have access to a disease modifying treatment after our successful clinical trial, DevelopAKUre, that showed a drug called nitisinone reduced the acid that causes AKU by 99.8%. We are now championing research into other therapies and co-therapies to realise our goal of curing AKU.

#### About Alkaptonuria & the AKU Society

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 fault 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 our successful European-wide clinical trial, DevelopAKUre, into a drug called nitisinone. This showed the drug was safe and effective in treating AKU and the drug received approval for treating AKU from the European Medicine Agency in 2020.

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 the majority of rare disease patients, often feel isolated because of their disease. Many patients have had years of misdiagnosis and misunderstanding from medical professionals. Often, their family finds it hard to understand what is wrong. This leaves many AKU patients feeling depressed and with a sense of isolation.

The AKU Society aims to change this by uniting patients at our biennial international and annual domestic patient workshops which helps us to grow the AKU community. We have also formed an innovative partnership with rare disease counselling service Rareminds CIC which is designed to address the often-neglected mental health of those suffering with AKU. This service allows us to bring people together to learn and share ways they can manage their mental health through techniques such as mindfulness and individual one-on-one counselling.

THE ALKAPTONURIA SOCIETY LTDREPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 30 JUNE 2024

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Our social media channels and website inform the public and medical professionals about our work and the advances in research into the disease. Our website also offers information in different languages and formats to make it accessible to those who either live abroad or in the UK with English as a second language, have specific learning difficulties, or with sensory issues.

We are also members of the Patient Information Forum (PIF) 'PIF Tick' programme. This kitemark shows that all medical information has gone through a strict production procedure designed to make it as accessible as possible including peer and user reviews.

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.

**Achievements and performance during the period**

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 check-ups, expert care, monitoring, and pain relief to patients based in the UK along with access to the drug nitisinone. 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. Medical research  
We are continuing to conduct research into developing potential treatments and cures for AKU. We work closely with the AKU research group at the University of Liverpool as well as a number of other universities and pharmaceutical companies around the world.  
Our current focus is developing a tyrosine reduction co-therapy to be used alongside nitisinone which would increase the safety and effectiveness of nitisinone treatment. We are also working on research in a number of other areas including gene therapy and mRNA therapy.
3. AKU Patient Workshop  
We had planned to host an AKU patient workshop in the autumn of 2022. Unfortunately, due to ongoing rail strikes this had to be postponed and the workshop will now be held in November 2024. Our workshop will be open to all UK AKU patients and their loved ones. We will host a number of specialist sessions aimed at supporting the management of the physical and mental impacts of AKU.
4. Mental Health Support  
We continue to provide AKU patients with access to mental health counselling from Rareminds CIC. Patients can arrange one-on-one counselling with experienced counsellors who have an understanding of rare diseases and AKU. This service is essential to providing support to our patients and their loved ones by helping them cope with the significant mental impact of their condition and the social isolation that AKU can cause.
5. AKU Global Registry  
We have now launched our AKU patient registry, collaborating with clinicians from around the world and working with Dendrite Ltd to design it. We are aiming to launch our registry in the UK in the Autumn of 2024 before expanding it to encompass the entire world.  
Our registry allows us to track the progression and prevalence of AKU around the world. This will help us to achieve universal access to treatment and allow us to accelerate our medical research into the condition.
6. International Scientific Conference on AKU  
In July 2023 we hosted our 13th International Scientific Conference on AKU in Bratislava, Slovakia. This was our largest conference to date, with over 70 in person attendees and over 30 virtual attendees joining us over the two days. Our conference allowed us to unite the AKU scientific community and forge a number of new relationships which will help us to drive our research into treating and curing AKU forward.

THE ALKAPTONURIA SOCIETY LTDREPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 30 JUNE 2024**OBJECTIVES AND ACTIVITIES****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 George Bou-Gharios 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.

**Grantmaking**

Our grantmaking is focused on supporting AKU research at the University of Liverpool, with which we have a 16 year partnership. The University of Liverpool is the world leader in AKU research and has several animal models of AKU that are used for testing out new therapies. All project proposals from the University of Liverpool are peer reviewed and amended accordingly before grant funding is agreed. The AKU Society believes that having such a close relationship with a world-class research institute over the long-term is the best use of our funds and ensures our continued success rather than spreading ourselves across many research institutes that don't have the same commitment to AKU. This ensures we can meet our objectives to increase our understanding of AKU and develop new and better treatments for this devastating disease.

**Volunteers**

We have a group of volunteers that are mainly from our AKU patient community and their families. They help with fundraising, patient support and sharing news about AKU.

**ACHIEVEMENT AND PERFORMANCE****Fundraising activities**

Trusts & Foundations - Our main source of income for specific projects:

Eleanor Rathbone - £3,000 - Patient Workshop

Strangward Foundation - £2,000 - Patient Workshop

Sir Samuel Scott of Yews Trust - £5,000 - Tyrosine Reduction Study

National Lottery Award - £10,000 - Patient Workshop

Saturday Hospital Fund - £2,000 - Patient Workshop

Hobson Charity Foundation - £5,000 - Patient Outreach Program

Jeans for Genes - £2,500 - Website redesign

EJPRD - £26,400 - AKU International Conference

VitaFlo - £5,000 - Sponsorship

Robert Luff Foundation - £20,000 - Tyrosine Reduction Study

Leach 14th Trust - £2,000 - Patient Outreach Programme

Corporate Partnerships

We have a corporate partnership with VitaFlo who we work closely with to provide our patient community with low protein products to assist their management of their condition. We received £5,000 towards our work.

**FINANCIAL REVIEW****Financial position**

We are currently holding significant reserves due to the large-scale scientific research that we conduct. The scale of these projects means that the fundraising for these studies takes place over multiple years. Due to this we must hold funding until the threshold of funding to begin the studies is met and then draw down on it each year for multi-year studies. The money we raise for these studies in our reserves are placed into restricted or designated funds relating to the specific project.

THE ALKAPTONURIA SOCIETY LTDREPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 30 JUNE 2024**FINANCIAL REVIEW****Principal funding sources**

The charity's principal funding sources is a grant 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 £319,392 (2023: £381,037) of which £222,774 (2023: £364,991) related to funding for projects upon which restrictions are placed. Total expenditure for the period was £307,370 (2023: £292,618).

At 30 June 2024 the Charity's total funds stood at £955,182 (2023: £943,160) of which £628,313 (2023: £716,029) represented restricted funds. Details of each restricted fund are shown in the notes to the accounts.

The Trustees have designated £112,500 (2023: £112,500) for use towards research costs over and above the £150,000 (2023: £150,000) of restricted research funds.

There is also a designated fund representing the net book value of fixed assets that can only be realised by disposing of tangible fixed assets.

**FUTURE PLANS**

We are continuing to fundraise for a tyrosine reduction study to counter the side effects of nitisinone treatment. We have already raised £590,000 and plan to approach companies and trusts to fundraise for a further £270,000 to continue the study.

We are also in the process of fundraising for a number of other research projects and patient support projects. These include an international AKU patient workshop, outreach campaigns, and mental health support.

**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.

**Organisational structure**

The AKU Society has a board of trustees and three staff (part-time CEO, full-time Head of Patient Support and Welfare, and full-time Fundraising and Communications Officer).

**Decision making**

Strategic and non-executive decisions are made by the board of trustees, which meets on a quarterly basis. Day-to-day and operational decisions are made by staff.

## THE ALKAPTONURIA SOCIETY LTD

### REPORT OF THE TRUSTEES FOR THE YEAR ENDED 30 JUNE 2024

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#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **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

##### **Key management remuneration**

The CEO is paid £53,318 per year. Pay and remuneration for staff is decided by the board of trustees and is reviewed on a regular basis and compared with similar positions in other similar sized charities.

##### **Wider network**

The AKU Society is a member of the Genetic Alliance UK, which brings together rare disease patient groups in the UK, and the Strategic Healthcare Alliance, which campaigns for fair policy for rare diseases. It is also a member of Eurordis (the European Organisation of Rare Diseases).

##### **Related parties**

The AKU Society works with the networks mentioned above to help share information about rare diseases, support rare disease patients, and ensure that policies for rare disease patients are equitable and fair.

#### **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  
Ms J Barnes

##### **Independent Examiner**

Matthew Pettifer FCA  
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 2024

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**REFERENCE AND ADMINISTRATIVE DETAILS**

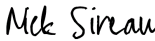
**Bankers**  
Co-operative Bank plc  
PO Box 250  
Delf House  
SKELMERSDALE  
WN8 6WT

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.

04/11/2024

Approved by order of the board of trustees on ..... and signed on its behalf by:

DocuSigned by:  
  
.....251710C999F34B7.....  
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 2024.

**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 member of the Institute of Chartered Accountants in England and Wales (ICAEW), 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.

DocuSigned by:  
  
7D289567F9E9483...

Julia Jones FCA

Archangel Accounting  
Burnham House  
Splash Lane  
Wyton  
Huntingdon  
PE28 7AF

Date: 04/11/2024  
Date: .....

THE ALKAPTONURIA SOCIETY LTD

STATEMENT OF FINANCIAL ACTIVITIES  
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)  
FOR THE YEAR ENDED 30 JUNE 2024

		Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
	Notes				
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	3	16,222	15,905	<b>32,127</b>	22,939
<b>Charitable activities</b>					
Grants	5	59,978	206,869	<b>266,847</b>	351,226
Investment income	4	18,506	-	<b>18,506</b>	4,741
Other income	6	1,912	-	<b>1,912</b>	2,131
<b>Total</b>		<b>96,618</b>	<b>222,774</b>	<b>319,392</b>	<b>381,037</b>
<b>EXPENDITURE ON</b>					
Raising funds	7	-	9,241	<b>9,241</b>	1,538
<b>Charitable activities</b>					
Charitable activities including research	8	1,258	296,871	<b>298,129</b>	291,080
<b>Total</b>		<b>1,258</b>	<b>306,112</b>	<b>307,370</b>	<b>292,618</b>
<b>NET INCOME</b>		<b>95,360</b>	<b>(83,338)</b>	<b>12,022</b>	<b>88,419</b>
Transfers between funds	17	4,378	(4,378)	-	-
<b>Net movement in funds</b>		<b>99,738</b>	<b>(87,716)</b>	<b>12,022</b>	<b>88,419</b>
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		227,131	716,029	<b>943,160</b>	854,741
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>326,869</b>	<b>628,313</b>	<b>955,182</b>	<b>943,160</b>

The notes form part of these financial statements

THE ALKAPTONURIA SOCIETY LTD (REGISTERED NUMBER: 04814120)BALANCE SHEET30 JUNE 2024

	Notes	2024 Total funds £	2023 Total funds £
<b>FIXED ASSETS</b>			
Tangible assets	14	2,270	3,338
<b>CURRENT ASSETS</b>			
Debtors	15	11,496	9,060
Cash at bank		1,050,038	1,028,630
		<b>1,061,534</b>	1,037,690
<b>CREDITORS</b>			
Amounts falling due within one year	16	(108,622)	(97,868)
<b>NET CURRENT ASSETS</b>		<b>952,912</b>	939,822
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<b>955,182</b>	943,160
<b>NET ASSETS</b>		<b>955,182</b>	943,160
<b>FUNDS</b>	17		
Unrestricted funds		326,869	227,131
Restricted funds		628,313	716,029
<b>TOTAL FUNDS</b>		<b>955,182</b>	943,160

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 June 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 30 June 2024 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.

The notes form part of these financial statements

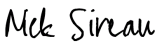
THE ALKAPTONURIA SOCIETY LTD (REGISTERED NUMBER: 04814120)

BALANCE SHEET - continued  
30 JUNE 2024

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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 04/11/2024  
.....and were signed on its behalf by:

DocuSigned by:  
  
.....2547710C999F34B7.....  
N T Sireau PhD - Trustee

THE ALKAPTONURIA SOCIETY LTDNOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 JUNE 2024**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.

THE ALKAPTONURIA SOCIETY LTDNOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024**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.

**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.

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.

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024

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**2. ACCOUNTING POLICIES - continued**

**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 at transaction value and subsequently measured at their settlement value.

**3. DONATIONS AND LEGACIES**

	2024	2023
	£	£
Donations	<u>32,127</u>	<u>22,939</u>

**4. INVESTMENT INCOME**

	2024	2023
	£	£
Deposit account interest	<u>18,506</u>	<u>4,741</u>



THE ALKAPTONURIA SOCIETY LTDNOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024**5. INCOME FROM CHARITABLE ACTIVITIES**

	2024	2023
Grants      Activity Research	<u>266,847</u>	<u>351,226</u>

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

	2024	2023
	£	£
National AKU Centre	180,544	169,920
The Hobson Charity	4,575	-
Woodroffe Benton – 2024 Patient Workshop contribution	1,750	-
Jeans for Genes	-	2,500
Hospital Saturday Fund	-	2,000
Swedish Orphan Biovitrum	-	4,251
VitaFlo	5,000	5,000
Awards for All	-	10,000
European Joint Programme on Rare Diseases	-	20,555
UKRI MRC	54,978	114,000
National Lottery Community Fund	20,000	-
Robert Luff Foundation	-	20,000
Eleanor Rathbone Charitable Trust	-	3,000
	<u>266,847</u>	<u>351,226</u>

**6. OTHER INCOME**

	2024	2023
	£	£
Other income	<u>1,912</u>	<u>2,131</u>

**7. RAISING FUNDS****Raising donations and legacies**

	2024	2023
	£	£
Costs of generating income	<u>9,241</u>	<u>1,298</u>

**Other trading activities**

	2024	2023
	£	£
Bad debts	<u>-</u>	<u>240</u>

THE ALKAPTONURIA SOCIETY LTDNOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024**8. CHARITABLE ACTIVITIES COSTS**

	Direct Costs £	Support costs (see note 9) £	Totals £
Research	<b>277,257</b>	<b>20,872</b>	<b>298,129</b>

**9. SUPPORT COSTS**

	Governance costs £
Research	<b>20,872</b>

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

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

	2024 £	2023 £
Depreciation - owned assets	<b>1,135</b>	2,029

**11. TRUSTEES' REMUNERATION AND BENEFITS**

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

	2024 £	2023 £
Trustees' salaries	<b>53,318</b>	53,779
Trustees' social security	<b>3,665</b>	3,574
Trustees' pension contributions	<b>2,666</b>	2,689
	<b>59,649</b>	60,042

**Trustees' expenses**

There were no trustees' expenses paid for the year ended 30 June 2024 nor for the year ended 30 June 2023.

THE ALKAPTONURIA SOCIETY LTDNOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024**12. STAFF COSTS**

	<b>2024</b>	2023
	£	£
Wages and salaries	<b>120,237</b>	120,237
Social security costs	<b>7,516</b>	7,197
Other pension costs	<b>5,840</b>	6,012
	<b>133,593</b>	133,446

The staff costs relating to Key Management Personnel were £103,814 (2023: £101,547).

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

	<b>2024</b>	2023
Chief Executive Officer	<b>1</b>	1
Head of Patient Support and Welfare	<b>1</b>	1
Fundraising and Communications Officer	<b>1</b>	1
	<b>3</b>	3

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

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	9,238	13,701	22,939
<b>Charitable activities</b>			
Research	-	351,226	351,226
Investment income	4,741	-	4,741
Other income	2,067	64	2,131
<b>Total</b>	<b>16,046</b>	<b>364,991</b>	<b>381,037</b>
<b>EXPENDITURE ON</b>			
Raising funds	-	1,538	1,538
<b>Charitable activities</b>			
Research	4,757	286,323	291,080
<b>Total</b>	<b>4,757</b>	<b>287,861</b>	<b>292,618</b>
<b>NET INCOME/(EXPENDITURE)</b>	<b>11,289</b>	<b>77,130</b>	<b>88,419</b>
Transfers between funds	(269)	269	-
<b>Net movement in funds</b>	<b>11,020</b>	<b>77,399</b>	<b>88,419</b>

THE ALKAPTONURIA SOCIETY LTDNOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024**13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES – continued**

	Unrestricted funds £	Restricted funds £	Total funds £
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	216,111	638,630	854,741
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u>227,131</u>	<u>716,029</u>	<u>943,160</u>

**14. TANGIBLE FIXED ASSETS**

	Plant and machinery £
<b>COST</b>	
At 1 July 2023	<b>15,064</b>
Additions	-
Disposals	<b>(11,658)</b>
At 30 June 2024	<b>3,406</b>
<b>DEPRECIATION</b>	
At 1 July 2023	<b>11,726</b>
Charge for year	<b>1,136</b>
Eliminated on disposal	<b>(11,726)</b>
At 30 June 2024	<b>1,136</b>
<b>NET BOOK VALUE</b>	
At 30 June 2024	<b>2,270</b>
At 30 June 2023	<b>3,338</b>

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

	2024 £	2023 £
Trade debtors	-	6,000
Prepayments and accrued income	<b>11,496</b>	<b>3,060</b>
	<u><b>11,496</b></u>	<u><b>9,060</b></u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024

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

	2024 £	2023 £
Trade creditors	920	135
Other creditors	3,402	686
Accruals and deferred income	104,300	97,047
	<u>108,622</u>	<u>97,868</u>

Deferred income comprises:	Deferred Income b.f	Received 2023/24	Deferred Income c.f	Income 2023/24
National AKU Centre	93,555	197,289	104,300	180,544
Total deferred income	<u>93,555</u>	<u>197,289</u>	<u>104,300</u>	<u>180,544</u>

**17. MOVEMENT IN FUNDS**

	At 1/7/23 £	Net movement in funds £	Transfers between funds £	At 30/06/2024 £
<b>Unrestricted funds</b>				
Combating Tyrosinaemia in AKU	-	54,978	-	54,978
General Fund	111,186	40,314	4,485	155,985
Designated Fixed Asset Fund	3,338	68	-	3,406
Designated Royalties	107	-	(107)	-
Designated Research Fund	112,500	-	-	112,500
	<u>227,131</u>	<u>95,360</u>	<u>4,378</u>	<u>326,869</u>
<b>Restricted funds</b>				
Childwick Trust	58,613	-	-	58,613
Breaking Down Barriers	8,928	-	(8,928)	-
SOBI	2,561	-	2,001	4,562
VitaFlo AKU recipe book	10,000	-	(10,000)	-
Tyrosine Degradation Study	355,125	(75,954)	-	279,171
Patient Workshop	30,380	15,240	-	45,620
SOFIA-Paediatric Study	47,095	-	-	47,095
Research Fund	150,000	-	-	150,000
European Joint Programme on Rare Diseases	15,328	(20,663)	5,335	-
National AKU Centre	-	5,682	8,928	14,610
Patient Registry	22,769	(11,231)	-	11,538
Homogentisic Acid Studies	17,104	-	-	17,104
SOBI - Translation Project	2,000	-	(2,000)	-
Education Outreach Programme	(4,575)	4,575	-	-
Website Fund	701	(987)	286	-
	<u>716,029</u>	<u>(83,338)</u>	<u>(4,378)</u>	<u>628,313</u>
<b>TOTAL FUNDS</b>	<u>943,160</u>	<u>12,022</u>	<u>-</u>	<u>955,182</u>

THE ALKAPTONURIA SOCIETY LTDNOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024**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>			
Combatting Tyrosinaemia in AKU	54,978	-	54,978
General Fund	41,640	(1,326)	40,314
Designated Fixed Asset Fund	-	68	68
	<u>96,618</u>	<u>(1,258)</u>	<u>95,360</u>
<b>Restricted funds</b>			
National AKU Centre	180,544	(174,862)	5,682
Tyrosine Degradation Study	-	(75,954)	(75,954)
Patient Workshop	30,500	(15,260)	15,240
European Joint Programme on Rare Diseases	3,386	(24,049)	(20,663)
Patient Registry	3,769	(15,000)	(11,231)
Education Outreach Programme	4,575	-	4,575
Website Fund	-	(987)	(987)
	<u>222,774</u>	<u>(306,112)</u>	<u>83,338</u>
<b>TOTAL FUNDS</b>	<u><u>319,392</u></u>	<u><u>(307,370)</u></u>	<u><u>12,022</u></u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024

**17. MOVEMENT IN FUNDS - continued**

**Comparatives for movement in funds**

**MOVEMENT IN FUNDS**

	At 1/7/22	Net movement in funds	Transfers between funds	At 30/6/23
	£	£	£	£
<b>Unrestricted funds</b>				
General Fund	101,067	13,292	(3,173)	111,186
Designated Fixed Asset Fund	2,437	(2,003)	2,904	3,338
Designated Royalties	107	-	-	107
Designated Research Fund	112,500	-	-	112,500
	<u>216,111</u>	<u>11,289</u>	<u>(269)</u>	<u>227,131</u>
<b>Restricted funds</b>				
Childwick Trust	58,613	-	-	58,613
Breaking Down Barriers	10,116	(1,188)	-	8,928
SOBI	2,590	(29)	-	2,561
VitaFlo AKU recipe book	5,000	5,000	-	10,000
Bedfordshire Support and Social Fund	2,032	(2,301)	269	-
Tyrosine Degradation Study	305,270	49,855	-	355,125
Patient Workshop	10,658	19,722	-	30,380
SOFIA-Paediatric Study	47,095	-	-	47,095
Research Fund	150,000	-	-	150,000
European Joint Programme on Rare Diseases	(1,591)	16,919	-	15,328
Patient Registry	29,567	(6,798)	-	22,769
Homogentisic Acid Studies	17,280	(176)	-	17,104
SOBI - Translation	2,000	-	-	2,000
Education Outreach Programme	-	(4,575)	-	(4,575)
Website Fund	-	701	-	701
	<u>638,630</u>	<u>77,130</u>	<u>269</u>	<u>716,029</u>
<b>TOTAL FUNDS</b>	<u><u>854,741</u></u>	<u><u>88,419</u></u>	<u><u>-</u></u>	<u><u>943,160</u></u>

THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024

**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	16,046	(2,754)	13,292
Designated Fixed Asset Fund	-	(2,003)	(2,003)
	<u>16,046</u>	<u>(4,757)</u>	<u>11,289</u>
<b>Restricted funds</b>			
National AKU Centre	169,984	(169,984)	-
Breaking Down Barriers	-	(1,188)	(1,188)
SOBI	-	(29)	(29)
VitaFlo AKU recipe book	5,000	-	5,000
Bedfordshire Support and Social Fund	-	(2,301)	(2,301)
Tyrosine Degradation Study	139,000	(89,145)	49,855
Patient Workshop	19,750	(28)	19,722
European Joint Programme on Rare Diseases	20,555	(3,636)	16,919
Patient Registry	8,202	(15,000)	(6,798)
Homogentisic Acid Studies	-	(176)	(176)
Education Outreach Programme	-	(4,575)	(4,575)
Website Fund	2,500	(1,799)	701
	<u>364,991</u>	<u>(287,861)</u>	<u>77,130</u>
<b>TOTAL FUNDS</b>	<u>381,037</u>	<u>(292,618)</u>	<u>88,419</u>

**Combatting Tyrosinaemia in AKU**

This is funding we have secured from a variety of sources to research new treatments for reducing excess tyrosine caused by nitrosinone therapy in AKU and thereby prevent its side effects.

**Body to Mind Programme**

Funding from the National Lottery Community Fund for the provision of a confidential telephone and online counselling service for all patients and family members.

**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.

**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.

**Education Outreach Fund**

Funding from Hobson Trust to attend the RCN congress to further the educational outreach program.

**European Joint Programme on Rare Diseases**

Funding for the rare diseases scientific workshop in Brussels.

**Homogentisic Acid Studies**

Funding from the Royal Liverpool University Hospital for studies into Homogentisic acid by the Antimicrobial Resistance Centre.



THE ALKAPTONURIA SOCIETY LTD

NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 30 JUNE 2024

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**17. MOVEMENT IN FUNDS - continued**

**National AKU Centre**

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

**Patient Registry**

Crowd source and other funding to support the development and implementation of AKU registry to allow AKU patients and treatments data collection.

**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 next patient workshop.

**Research fund**

This comprises funds received from various sources to fund research into Alkaptonuria.

**SOBI**

Grants from Swedish Orphan Biovitrium AB, including to produce two videos aimed at educating the public, patients, policymakers and health care professionals about living with AKU and the success of the DevelopAKU consortium.

**SOBI Translation**

Funding to translate and information leaflet into eight identified languages for international AKU patients.

**SOFIA Paediatric Study**

Donation from Trysil Charitable Trust towards a Paediatric Study.

**Tyrosine Degradation Study**

Funding from individual donors, Pilkintons Charitable Trust and the Hamamelius Trust towards the costs of research into tyrosine degradation and inhibition.

**Vitaflo**

Sponsorship from Vitaflo for the AKU recipe book.

**Website**

Funding from Jeans for Genes to rewrite and design the website.

**Designated Fixed Asset Fund**

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

**Designated Research**

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

**Transfers between funds**

There were no material transfers between funds in the year.

THE ALKAPTONURIA SOCIETY LTD

DETAILED STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 30 JUNE 2024

**18. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 30 June 2024.

**19. INDEPENDENT EXAMINERS' REMUNERATION**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Fees relating to independent examination	<u><u>-</u></u>	<u><u>3,292</u></u>