

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 2022**  
**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 2022**

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**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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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 2022. 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).

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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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 and two-yearly international workshops. Along with hands-on support at the National Alkaptonuria Centre (NAC) and with accessing the care patients deserve.

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, often 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 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

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 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 into a drug called nitisinone. This showed the drug was safe and effective in treating AKU.

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 and with a sense of isolation.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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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 innovative partnership with rare disease counselling service Rareminds 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 pain through techniques such as mindfulness and individual one-on-one counselling.

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 are either 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 accurate as possible, including peer and user reviews.

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.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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**OBJECTIVES AND ACTIVITIES**

**Achievements and performance during the period**

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 Scotland and England 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.

COVID-19 continued to impact the way in which the NAC operated. The NAC closed in March 2020. It reopened in September 2020 but then closed again and didn't reopen until September 2021. Following approval from the Welsh Assembly and Northern Irish Assembly respectively, patients from Wales and Northern Ireland are now able to access treatment at the NAC.

June 2022 marked the 10th anniversary of the NAC being in operation which we celebrated with the patient community and NAC staff to highlight their work and the impact the NAC has had on the patient community.

**2. Nitisinone and Medical Research**

In 2020 the European Medicines Agency (EMA) and the European Commission (EC) granted a license for the use of nitisinone to treat AKU. This is the first effective treatment for the disease and is a culmination of years of research by the DevelopAKUre consortium. Now that the drug is licensed to treat AKU, we continue to assist all partners pursuing licensing and ensuring equity of access. Following studies at the NAC, the recommended dosage of nitisinone is in the process of being increased from 2mg per day to 10mg per day.

We are continuing to research for potential treatments and cures for AKU, with our current projects including a tyrosine reduction co-therapy, an mRNA therapy, and a gene therapy for AKU.

We have also been preparing a study, called SOFIA-Paediatric, which will investigate the way in which AKU begins to present in children. With this knowledge we will be able to determine the best age at which to begin nitisinone treatment to limit the physical damage AKU inflicts upon children with the condition. This study is due to begin in the Autumn of 2022 and will be coordinated by the Birmingham Women's and Children's Hospital for a duration of two years.

We are also in the early stages of planning a study to identify a tyrosine-reduction co-therapy. Although nitisinone is a life-changing treatment that can slow, or even halt, the symptoms of AKU, it leads to a serious condition known as hypertyrosinaemia. This condition can potentially cause blindness, severe skin rashes, and brain damage if a strictly controlled diet is not followed. Developing a tyrosine reduction co-therapy will significantly improve the safety of nitisinone treatment and end the restrictions currently placed on the lifestyle of AKU patients. We have begun preliminary research into a tyrosine reduction treatment, a project which is being led by Prof George Bou-Gharios and Dr Brendan Norman at the University of Liverpool. We have already secured £500,000 in funding for this study and are continuing to fundraise.

**3. Mental Health Support**

We have been providing AKU patients with access to mental health counselling from Raremind CIC. Patients are able to arrange one-on-one counselling with experienced counsellors who have an understanding of rare diseases and AKU in particular. 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.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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**OBJECTIVES AND ACTIVITIES**

**4. AKU Global Registry**

In collaboration with the NAC, we are in the process of establishing a global AKU registry. The registry will allow us to track the natural progression of the disease, identify new AKU patients, play a key role in establishing additional national AKU Societies, and drive forward our efforts to secure universal access to nitisinone. In late 2021, we launched a crowd-funding campaign to raise funds for the registry and we raised over £30,000 towards the cost of the registry.

**5. International Scientific Conference on AKU**

In May 2022 we hosted our 12th International Conference on AKU in Brussels, Belgium. Following two-years of delays from COVID-19, we were finally able to reunite the AKU scientific community to discuss current and future research into the disease. Over 100 people joined us at the conference, and we created a number of useful connections which will help us to drive forward research into treatments and cures for AKU.

**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), and the Royal Liverpool and Broadgreen University Hospital Trust (with Prof L Ranganath at the Department of Clinical Chemistry).

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**

**Charitable activities**

As described at the start of this trustees report, our objectives focus on patient support, community building and medical research. All our work over the past 12 months and since we were founded has focused on these three areas, as this report shows.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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**ACHIEVEMENT AND PERFORMANCE**

**Fundraising activities**

Our fundraising is currently focused primarily on medical research into reducing the excessive tyrosine caused by nitisinone treatment. So far, we have been very successful with this by funding a fellowship at the University of Liverpool which supports Dr Brendan Norman over the next three years. However, there is a big need for further funding in order to take this further into animal studies and clinical studies.

Further fundraising focuses on activities such as our annual AKU patient workshop, which will take place in November 2022 in Liverpool, and our international patient workshop, which we hope will take place in 2023.

The AKU Society does not use any external professional or commercial fundraisers. All fundraising is done in-house and is focused mainly on trusts and foundations. No complaints have been received by the charity in relation to fundraising activities, and the focus on raising funds from trusts and foundations rather than individual members of the public ensures that vulnerable people and other members of the public are protected when fundraising activities are undertaken.

**Internal and external factors**

COVID-19 impacted our work significantly. In-person patient visits to the NAC were suspended during the pandemic, our AKU patient workshops had to be cancelled or held virtually (this resulted in having to return £10,000 in funding to Awards for All), and our AKU Scientific Workshop was delayed for over two years.

**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.

**Principal funding sources**

The charity's principal funding sources are grants from UKRI MRC 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 £586,708 (2021: £335,222) of which £566,349 (2021: £268,302) related to funding for projects upon which restrictions are placed. Total expenditure for the period was £300,351 (2021: £272,750).

At 30 June 2022 the Charity's total funds stood at £854,741 (2021:£568,384) of which £638,630 (2021:£316,442) represented restricted funds. Details of each restricted fund are shown in the notes to the accounts.

The Trustees have designated £112,500 (2021: £112,500) for use towards research costs over and above the £150,000 (2021: £150,000) of restricted research funds.

There are also two designated funds representing the net book value of fixed assets that can only be realised by disposing of tangible fixed assets, and royalties which have been received for a book shared between various organisations which the charity receives and distributes.



**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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**FINANCIAL REVIEW**

**Funds in deficit**

At the year end there was a small deficit on the European Joint Programme on Rare Diseases fund. This will be covered by the remaining 20% of the grant funding which has been withheld until the end of the project.

**FUTURE PLANS**

We are continuing to fundraise for a tyrosine reduction study to counter the side effects of nitisinone treatment. This study builds on preliminary research we have conducted with our partners at the University of Liverpool and forms the next phase of our research into treating and curing AKU. We have already secured £500,000 of funding for this study and plan to approach companies and trusts to fundraise a further £280,000.

In November 2022 our in-person AKU patient workshops are returning following two years of virtual events due to the pandemic. All UK AKU patients will be invited to attend the workshop at the Bluecoat Centre, Liverpool, where we will host a number of specialist sessions to help patients manage their physical disability and mental health. In the summer of 2023 we are also planning to host an international AKU patient workshop which follows a similar programme to our UK workshops but provides the opportunity for patients from around the world to attend and form friendships within the community.

This year we are also planning on launching our global AKU Registry which we successfully crowdfunded for. This registry will initially launch in the UK before expanding to encompass the world. The registry will allow us to track the natural history of AKU and help us to diagnose more patients and connect them with the support and treatment they deserve.

This year, our SOFIA-Paediatric (Subchondral Ochronotic Features in Alkaptonuria in the paediatric age group) study will begin. This study, following on from the SOFIA (Subclinical Ochronotic Features in Alkaptonuria) trial as part of the DevelopAKUre study, will aim to identify the age at which the physical symptoms of AKU begin to present in children. This information will allow us to determine the best age at which to begin nitisinone treatment in children allowing them to grow up without the symptoms of AKU developing.

We are also planning to fundraise £3,000 to redesign and rewrite our website. Our website is outdated and difficult to navigate. We recognise the need to create an accessible website, particularly for the elderly and those who don't speak English as a first language or have specific learning difficulties. Our new website will allow patients and medical professionals to quickly access relevant news and information on AKU.

**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.

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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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 £50,000 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

**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

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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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

**STATEMENT OF TRUSTEES' RESPONSIBILITIES**

The trustees (who are also the directors of The Alkaptonuria Society Ltd for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland"

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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 ..... 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 2022.

**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  
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 2022**

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	3	20,029	284,849	304,878	86,393
<b>Charitable activities</b>					
Research		-	281,500	281,500	248,760
Investment income	4	330	-	330	69
<b>Total</b>		<u>20,359</u>	<u>566,349</u>	<u>586,708</u>	<u>335,222</u>
<b>EXPENDITURE ON</b>					
Raising funds	6	-	600	600	2,042
<b>Charitable activities</b>	7				
Research		<u>54,933</u>	<u>244,818</u>	<u>299,751</u>	<u>270,708</u>
<b>Total</b>		<u>54,933</u>	<u>245,418</u>	<u>300,351</u>	<u>272,750</u>
<b>NET INCOME/(EXPENDITURE)</b>		(34,574)	320,931	286,357	62,472
<b>Transfers between funds</b>	16	<u>(1,257)</u>	<u>1,257</u>	<u>-</u>	<u>-</u>
<b>Net movement in funds</b>		(35,831)	322,188	286,357	62,472
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		251,942	316,442	568,384	505,912
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u><u>216,111</u></u>	<u><u>638,630</u></u>	<u><u>854,741</u></u>	<u><u>568,384</u></u>

The notes form part of these financial statements

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

**BALANCE SHEET**  
**30 JUNE 2022**

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
<b>FIXED ASSETS</b>					
Tangible assets	13	2,437	-	2,437	3,282
<b>CURRENT ASSETS</b>					
Debtors	14	-	7,053	7,053	8,455
Cash at bank		214,079	729,142	943,221	654,445
		<u>214,079</u>	<u>736,195</u>	<u>950,274</u>	<u>662,900</u>
<b>CREDITORS</b>					
Amounts falling due within one year	15	(405)	(97,565)	(97,970)	(97,798)
<b>NET CURRENT ASSETS</b>		<u>213,674</u>	<u>638,630</u>	<u>852,304</u>	<u>565,102</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>216,111</u>	<u>638,630</u>	<u>854,741</u>	<u>568,384</u>
<b>NET ASSETS</b>		<u>216,111</u>	<u>638,630</u>	<u>854,741</u>	<u>568,384</u>
<b>FUNDS</b>	16				
Unrestricted funds:					
General Fund				101,067	136,053
Designated Fixed Asset Fund				2,437	3,282
Designated Royalties				107	107
Designated Research Fund				112,500	112,500
				<u>216,111</u>	<u>251,942</u>
Restricted funds				<u>638,630</u>	<u>316,442</u>
<b>TOTAL FUNDS</b>				<u>854,741</u>	<u>568,384</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 June 2022.

The members have not required the company to obtain an audit of its financial statements for the year ended 30 June 2022 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- 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

**BALANCE SHEET - continued**

**30 JUNE 2022**

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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 ..... and were signed on its behalf by:

.....  
N T Sireau PhD - Trustee

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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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 2022**

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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.

**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 2022**

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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**

	<b>2022</b>	2021
	<b>£</b>	£
Donations	<b>304,878</b>	86,393

**4. INVESTMENT INCOME**

	<b>2022</b>	2021
	<b>£</b>	£
Deposit account interest	<b>330</b>	69

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**5. INCOME FROM CHARITABLE ACTIVITIES**

		<b>2022</b>	2021
	Activity	£	£
Grants	Research	<b>281,500</b>	248,760

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

	<b>2022</b>	2021
	£	£
Childwick Trust	-	15,000
National AKU Centre	<b>157,740</b>	129,740
Swedish Orphan Biovitrum	<b>11,456</b>	17,120
Vitaflo	<b>5,000</b>	5,000
RLUH - Antimicrobial Resistance Centre	-	28,800
SENSE - Pears Grant	-	8,100
National Lottery Community Fund - COVID response grant	<b>(10,000)</b>	45,000
European Joint Programme on Rare Diseases	<b>24,534</b>	-
UKRI MRC	<b>72,770</b>	-
Robert Luff Foundation	<b>20,000</b>	-
	<b>281,500</b>	248,760

**6. RAISING FUNDS**

**Raising donations and legacies**

	<b>2022</b>	2021
	£	£
Costs of generating income	<b>600</b>	2,042

**7. CHARITABLE ACTIVITIES COSTS**

	Direct Costs £	Support costs (see note 8) £	Totals £
Research	<b>294,599</b>	<b>5,152</b>	<b>299,751</b>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**8. SUPPORT COSTS**

	Governance costs
	£
Research	<u><u>5,152</u></u>

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

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

	2022	2021
	£	£
Depreciation - owned assets	<u><u>2,458</u></u>	<u><u>2,252</u></u>

**10. 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.

	2022	2021
	£	£
Trustees' salaries	50,243	46,876
Trustees' social security	4,184	3,455
Trustees' pension contributions	2,527	2,343
	<u><u>56,955</u></u>	<u><u>52,663</u></u>

**Trustees' expenses**

There were no trustees' expenses paid for the year ended 30 June 2022 nor for the year ended 30 June 2021.

**11. STAFF COSTS**

	2022	2021
	£	£
Wages and salaries	134,974	138,545
Social security costs	10,684	9,673
Other pension costs	6,493	6,928
	<u><u>152,151</u></u>	<u><u>155,146</u></u>

The staff costs relating to Key Management Personnel were £122,379 (2021: £125,265).

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**11. STAFF COSTS - continued**

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

	<b>2022</b>	2021
Chief Executive Officer	<b>1</b>	1
Head of Projects and Communications	<b>1</b>	1
Head of Patient Support and Welfare	<b>1</b>	1
Fundraising Manager	<b>1</b>	1
	<u><b>4</b></u>	<u>4</u>

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

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	61,851	24,542	86,393
<b>Charitable activities</b>			
Research	5,000	243,760	248,760
Investment income	69	-	69
<b>Total</b>	<u>66,920</u>	<u>268,302</u>	<u>335,222</u>
<b>EXPENDITURE ON</b>			
Raising funds	-	2,042	2,042
<b>Charitable activities</b>			
Research	40,347	230,361	270,708
<b>Total</b>	<u>40,347</u>	<u>232,403</u>	<u>272,750</u>
<b>NET INCOME</b>	26,573	35,899	62,472
<b>Transfers between funds</b>	1,654	(1,654)	-
<b>Net movement in funds</b>	28,227	34,245	62,472
<b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>	223,715	282,197	505,912
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u>251,942</u>	<u>316,442</u>	<u>568,384</u>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**13. TANGIBLE FIXED ASSETS**

	Plant and machinery £
<b>COST</b>	
At 1 July 2021	<b>17,641</b>
Additions	<b>1,615</b>
Disposals	<b>(7,098)</b>
	<hr/>
At 30 June 2022	<b>12,158</b>
	<hr/>
<b>DEPRECIATION</b>	
At 1 July 2021	<b>14,359</b>
Charge for year	<b>2,458</b>
Eliminated on disposal	<b>(7,096)</b>
	<hr/>
At 30 June 2022	<b>9,721</b>
	<hr/>
<b>NET BOOK VALUE</b>	
At 30 June 2022	<b>2,437</b>
	<hr/> <hr/>
At 30 June 2021	<b>3,282</b>
	<hr/> <hr/>

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

	2022 £	2021 £
Trade debtors	<b>240</b>	600
Prepayments and accrued income	<b>6,813</b>	7,855
	<hr/>	<hr/>
	<b>7,053</b>	8,455
	<hr/> <hr/>	<hr/> <hr/>

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

	2022 £	2021 £
Trade creditors	<b>405</b>	166
Other creditors	<b>686</b>	877
Accruals and deferred income	<b>96,879</b>	96,755
	<hr/>	<hr/>
	<b>97,970</b>	97,798
	<hr/> <hr/>	<hr/> <hr/>

Deferred income comprises:	<b>Deferred Income b.f</b>	<b>Received 2022</b>	<b>Deferred Income c.f</b>	<b>Income 2022</b>
National AKU Centre	93,555	157,740	93,555	157,740
	<hr/>	<hr/>	<hr/>	<hr/>
Total deferred income	93,555	157,740	93,555	157,740
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**16. MOVEMENT IN FUNDS**

	At 1/7/21 £	Net movement in funds £	Transfers between funds £	At 30/6/22 £
<b>Unrestricted funds</b>				
General Fund	136,052	(32,113)	(2,872)	101,067
Designated Fixed Asset Fund	3,283	(2,461)	1,615	2,437
Designated Royalties	107	-	-	107
Designated Research Fund	112,500	-	-	112,500
	<u>251,942</u>	<u>(34,574)</u>	<u>(1,257)</u>	<u>216,111</u>
<b>Restricted funds</b>				
National AKU Centre	6,623	(5,008)	(1,615)	-
Childwick Trust	58,613	-	-	58,613
Breaking Down Barriers	10,116	-	-	10,116
SOBI	11,256	(8,666)	-	2,590
Vitaflo AKU recipe book	-	5,000	-	5,000
Bedfordshire Support and Social Fund	2,032	-	-	2,032
Tyrosine Degradation Study	-	305,270	-	305,270
Patient Workshop	22,409	(11,751)	-	10,658
SOFIA-Paediatric Study	34,417	12,678	-	47,095
Body to Mind Programme	3,696	(6,568)	2,872	-
Research Fund	150,000	-	-	150,000
European Joint Programme on Rare Diseases	-	(1,591)	-	(1,591)
Patient Registry	-	29,567	-	29,567
Homogentisic Acid Studies	17,280	-	-	17,280
SOBI - Translation	-	2,000	-	2,000
	<u>316,442</u>	<u>320,931</u>	<u>1,257</u>	<u>638,630</u>
<b>TOTAL FUNDS</b>	<u>568,384</u>	<u>286,357</u>	<u>-</u>	<u>854,741</u>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**16. 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	20,359	(52,472)	(32,113)
Designated Fixed Asset Fund	-	(2,461)	(2,461)
	<u>20,359</u>	<u>(54,933)</u>	<u>(34,574)</u>
<b>Restricted funds</b>			
National AKU Centre	157,740	(162,748)	(5,008)
SOBI	(360)	(8,306)	(8,666)
Vitaflo AKU recipe book	5,000	-	5,000
Tyrosine Degradation Study	342,770	(37,500)	305,270
Patient Workshop	(10,000)	(1,751)	(11,751)
SOFIA-Paediatric Study	12,678	-	12,678
Body to Mind Programme	-	(6,568)	(6,568)
European Joint Programme on Rare Diseases	24,534	(26,125)	(1,591)
Patient Registry	26,567	3,000	29,567
SOBI - Translation	7,420	(5,420)	2,000
	<u>566,349</u>	<u>(245,418)</u>	<u>320,931</u>
<b>TOTAL FUNDS</b>	<u><u>586,708</u></u>	<u><u>(300,351)</u></u>	<u><u>286,357</u></u>



**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**16. MOVEMENT IN FUNDS - continued**

**Comparatives for movement in funds**

	At 1/7/20 £	Net movement in funds £	Transfers between funds £	At 30/6/21 £
<b>Unrestricted funds</b>				
General Fund	69,728	66,325	-	136,053
Designated Fixed Asset Fund	3,880	(2,252)	1,654	3,282
Designated Royalties	107	-	-	107
Designated Research Fund	150,000	(37,500)	-	112,500
	<u>223,715</u>	<u>26,573</u>	<u>1,654</u>	<u>251,942</u>
<b>Restricted funds</b>				
National AKU Centre	190,135	(38,858)	(144,654)	6,623
Childwick Trust	43,613	15,000	-	58,613
Breaking Down Barriers	10,391	(275)	-	10,116
SOBI	1,617	9,639	-	11,256
Bedfordshire Support and Social Fund	2,032	-	-	2,032
Tyrosine Degradation Study	7,000	-	(7,000)	-
Patient Workshop	17,409	5,000	-	22,409
SOFIA-Paediatric Study	10,000	24,417	-	34,417
Homogentisic Acid Studies	-	17,280	-	17,280
Body to Mind Programme	-	3,696	-	3,696
Research Fund	-	-	150,000	150,000
	<u>282,197</u>	<u>35,899</u>	<u>(1,654)</u>	<u>316,442</u>
<b>TOTAL FUNDS</b>	<u>505,912</u>	<u>62,472</u>	<u>-</u>	<u>568,384</u>

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

**16. 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	66,920	(595)	66,325
Designated Fixed Asset Fund	-	(2,252)	(2,252)
Designated Research Fund	-	(37,500)	(37,500)
	<u>66,920</u>	<u>(40,347)</u>	<u>26,573</u>
<b>Restricted funds</b>			
National AKU Centre	124,865	(163,723)	(38,858)
Childwick Trust	15,000	-	15,000
Breaking Down Barriers	-	(275)	(275)
SOBI	17,120	(7,481)	9,639
Patient Workshop	5,000	-	5,000
SOFIA-Paediatric Study	24,417	-	24,417
Homogentisic Acid Studies	28,800	(11,520)	17,280
Body to Mind Programme	53,100	(49,404)	3,696
	<u>268,302</u>	<u>(232,403)</u>	<u>35,899</u>
<b>TOTAL FUNDS</b>	<u>335,222</u>	<u>(272,750)</u>	<u>62,472</u>

**Bedfordshire Support and Social Fund**

Funding from the Wixamtree Trust supporting AKU patients in Bedfordshire.

**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.

**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.

**National AKU Centre**

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

**Patient Registry**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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**16. MOVEMENT IN FUNDS - continued**

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 January 2022 patient workshop.

**Research fund**

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

**SOBI**

Grants from Swedish Orphan Biovitrum 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.

**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**

£1,615 was transferred from the NAC fund to the designated fixed asset funds, representing fixed assets purchased in the year.

£2,872 was transferred from the general fund to the Body to Mind programme to cover the shortfall in funding on the project.

**THE ALKAPTONURIA SOCIETY LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 30 JUNE 2022**

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**17. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 30 June 2022.

**18. INDEPENDENT EXAMINERS' REMUNERATION**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Fees relating to independent examination	<b>3,292</b>	3,200