

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

England & Wales · Charity number 273670

## Details

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Other names	THE NATIONAL SOCIETY FOR PHENYLKETONURIA AND ALLIED DISORDERS LIMITED, THE NSPKU
Status	Registered
Legal form	Charitable company
Company number	<a href="#">01256124</a>
Registered	1977-06-16
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Address	NSPKU (Uk) Ltd PO Box 862 Chesterfield Derbyshire S43 9FF
Phone	030 3040 1090
Email	<a href="mailto:info@nspku.org">info@nspku.org</a>
Website	<a href="http://www.nspku.org">www.nspku.org</a>

## Activities

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**Objects:** TO PROMOTE THE EDUCATIONAL MEDICAL AND SOCIAL WELFARE OF PERSONS SUFFERING FROM PHENYLKETONURIA AND SIMILAR DISORDERS CONTROLLED BY DIET, TO ESTABLISH AND MAINTAIN A FUND OR FUNDS FROM WHICH TO MAKE GRANTS FOR THE PURPOSE OF FULFILING THE OBJECTS OF THE ASSOCIATION. (FOR FURTHER DETAILS SEE CLAUSE 3 OF THE MEMORANDUM)

**Activities:** The Society exists to provide help and support to people with PKU and their families and carers. We continue to promote the education, medical and welfare of PKU sufferers.

## Classification

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- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

## Geography

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- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2024-10-31	£202,510	£166,869	-	-
2023-10-31	£158,065	£136,097	-	-
2022-10-31	£136,649	£114,969	-	-
2021-10-31	£90,060	£79,810	-	-
2020-10-31	£117,637	£93,606	-	-

## Trustees

Name	Role	Appointed
Amisha Bagri		2024-05-18
Anita MacDonald		2024-05-18
Caroline Graham		2024-02-20
Christopher Cassidy		2024-05-18
Dr Emma Vardy		2024-05-18
John Skidmore		2024-01-25
Kate Learoyd		2023-11-12
Paul Duncan McKellar		2025-11-30
Sara Louise Noble-Nesbitt		2024-02-01
Sarah Youssefi		2025-11-30
Tom Chimiak		2024-05-18

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**

England & Wales - Charity number 273670

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# Accounts

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**REGISTERED COMPANY NUMBER: 01256124 (England and Wales)**  
**REGISTERED CHARITY NUMBER: 273670**

**REPORT OF THE TRUSTEES AND**  
**UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 OCTOBER 2024**  
**FOR**  
**THE NATIONAL SOCIETY FOR PHENYLKETONURIA**  
**(UNITED KINGDOM) LIMITED**  
**(A COMPANY LIMITED BY GUARANTEE)**

Hayes & Co  
St Andrews House  
3 Tarleton Office Park  
Windgate  
Tarleton  
PR4 6JF

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

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for the year ended 31 October 2024**

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**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2024**

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 31 October 2024, which are prepared to meet the requirements for a directors' report and accounts for Companies Act purposes. 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 to the UK and Republic of Ireland (FRS 102) effective 1 January 2019).

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable in the UK and Republic of Ireland published.

**OBJECTIVES AND ACTIVITIES**

**Objectives and aims**

The objectives of the charity are to promote the educational, medical and social welfare of persons suffering from phenylketonuria and similar disorders controlled by diet, to establish or encourage research in phenylketonuria and related disorders, to establish and maintain a fund or funds from which to make grants for the purpose of fulfilling the objects of the society, to invite, procure, appeal for, collect and receive and accept subscriptions, donations, legacies and gifts of money, investments or other property. The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives, and in planning future objectives.

**Grantmaking policy**

The allocation of grants is decided on an individual basis as an application is made. The application where possible will be discussed by the Council of Management (anonymously if necessary) but if this is not possible a decision will be made by the senior officers and minutes taken at the next Committee of Management meeting. Where applicable, we shall seek guidance from our Medical Advisory Panel.

**Volunteers**

All members of the Council of Management are volunteers. They are encouraged to contribute freely to all discussions and decisions made by the Council. Meetings have minutes taken to reflect discussions, decisions and dissentions.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2024**

**ACHIEVEMENT AND PERFORMANCE**

Trustees' Report: Summary of Achievements 2023-2024

The National Society for Phenylketonuria (NSPKU) has had an exceptional year, with continued success in its advocacy, fundraising, research, and community support initiatives. As we reflect on the past 12 months, we are proud to highlight the remarkable progress made in improving the lives of people living with PKU, expanding our reach, and strengthening our influence in public health policy and awareness.

**1. Advocacy and Campaigning Success**

NSPKU has remained at the forefront of advocating for improved treatment access and support for individuals living with PKU. This year, our work has focused on:

- **Access to Treatment:** NSPKU has continued to campaign for better access to treatments such as sapropterin (Kuvan) and new therapies in development. We have worked closely with policymakers, healthcare leaders, and patient advocates to push for equitable access to medications and dietary support across all NHS regions.
- **Engagement with Parliament and Healthcare Bodies:** NSPKU representatives have taken PKU awareness to parliamentary discussions, meeting with MPs and government health officials to highlight the challenges of PKU management and the need for sustained NHS funding for treatment and dietary support.
- **Taking PKU Awareness to Parliament:** NSPKU representatives have actively engaged with MPs and policymakers, ensuring that PKU remains on the agenda. Our efforts have contributed to increased parliamentary awareness, particularly in discussions on healthcare funding, dietary management support, and the need for policy changes that would improve the lives of those with PKU.
- **NSPKU at the ESPKU Conference:** The society played a significant role in this year's European Society for PKU (ESPKU) Conference, held in the UK. The event provided an opportunity to collaborate on international best practices, share research updates, and strengthen alliances with global PKU advocates.
- **Campaigning for Fairer PKU Management Guidelines:** NSPKU has worked tirelessly to ensure that healthcare professionals, schools, and workplaces understand the unique dietary and medical needs of PKU individuals, with updated guidelines and policy proposals submitted to relevant authorities.

**2. Community Support and Engagement**

Providing direct support to PKU individuals and families remains central to NSPKU's mission. This year, we have expanded our services and educational initiatives, ensuring that people with PKU have access to expert guidance, emotional support, and essential resources.

- **Expansion of the NSPKU Helpline:** Our telephone and online support services have been enhanced to offer timely and personalised advice on PKU management, dietary challenges, and treatment options.
- **Educational Webinars and Resources:** NSPKU has hosted several online seminars with leading metabolic specialists and dietitians, ensuring PKU patients, parents, and caregivers have access to the latest medical guidance and research.
- **Edale Activity Weekend:** One of the most successful community events this year was the Edale Activity Weekend, which brought together children aged 8-12 living with PKU for a weekend of outdoor adventure, confidence-building, and peer support. The weekend, subsidised by NSPKU, was an opportunity for young people to develop social connections and practical skills for managing PKU.
- **Support for Schools and Nurseries:** The NSPKU has actively supported parents and educators, ensuring children with PKU receive appropriate dietary and medical accommodations. A key success has been Hurley's Nursery, which set an example by implementing a PKU-friendly meal plan and supporting dietary compliance for one of its pupils.

**3. Fundraising and Financial Growth**

The commitment and generosity of NSPKU's fundraisers have been outstanding, ensuring the society remains financially resilient and able to support its core activities. Key highlights include:

- **Total Fundraising Impact:** Over the past year, NSPKU's supporters have raised substantial funds, with fundraising efforts exceeding expectations.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2024**

- Race to £10K Challenge: This campaign saw runners across the UK unite to raise well over the £10,000 target for NSPKU, increasing awareness and community engagement.
- Corporate Donations and Grants: Significant contributions have been received from Reed Foundation (£10,000), The Geoffrey & Pauline Martin Charitable Trust (£10,000), Making a Difference Locally (MADL), and Chroma Recruitment.
- Community Fundraising Initiatives:
  - Isle of Wight Perimeter Walk raised £2,393 through an incredible endurance challenge.
  - London Bridges Walk raised over £2,000 with participants walking across 12 iconic London bridges in support of PKU.
  - Climbing Slieve Donard (Northern Ireland's highest peak) raised £4,126, led by PKU parents and supporters.
  - Fashion Show Fundraiser: Hosted by Inner Wheel Club of Roborough, raising £1,170 for NSPKU.
  - Firewalking for PKU: Brave fundraisers completed a firewalk challenge to support PKU awareness and funding.
  - Wedding and Birthday Donations: Many NSPKU supporters chose to donate in celebration of their milestones, including Frankie & Joe Clarke's wedding and Auntie Viv's 70th birthday, raising over £400 each.

**4. Research and Medical Advancements**

NSPKU continues to play an active role in advancing research and supporting the development of improved treatments. This year, we have:

- Collaborated with leading metabolic researchers and pharmaceutical companies to promote innovative treatment pathways, including gene therapy and synthetic probiotics.
- Provided updates on the impact of Sapropterin (Kuvan) two years after its initial NHS rollout, ensuring continued patient access and data collection on its effectiveness.
- Engaged with NHS metabolic teams to develop better treatment frameworks and dietary support plans for PKU patients.

**5. Future Goals and Strategic Priorities**

As we move into the next year, NSPKU remains dedicated to expanding its advocacy, support, and research efforts. Our strategic priorities include:

- Advocating for wider access to new PKU treatments and ensuring fair and consistent NHS coverage across all regions.
- Strengthening patient support services, including more personalised dietary advice, school support programs, and expanded helpline hours.
- Fostering international partnerships to collaborate on global PKU research and awareness initiatives.
- Investing in medical research, ensuring that PKU remains a focus for scientific and healthcare advancements.
- Enhancing community engagement by supporting local PKU groups and hosting more in-person and virtual support events.

**Conclusion**

This year has been one of significant progress, resilience, and unity within the PKU community. Through dedicated advocacy, tireless fundraising, and unwavering support, NSPKU has continued to make a meaningful impact on the lives of individuals with PKU and their families.

We express our deepest gratitude to every donor, fundraiser, advocate, and volunteer who has contributed to our mission. As we move forward, we remain committed to improving access to treatment, providing vital support services, and advocating for a future where PKU individuals can live their fullest lives.

Together, we are making a lasting difference.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2024**

**FINANCIAL REVIEW**

**Financial position**

The net incoming resources for the year were £ 35,641 (2023: £21,968) details of which are shown on the statement of Financial Activities.

**Principal funding sources**

The principal funding sources are donations, sponsorships and fund raising activities and are shown in the Statement of Financial Activities and in the notes to the accounts.

**Investment policy and objectives**

The society's policy is to hold surplus funds in building society and deposit accounts.

**Reserves policy**

At 31 October 2024 £16,211 (2023: £16,211) was held in the restricted research fund, £5,420 was held in a restricted fund for a new website (2023: £15,060), £410 was held in a restricted fund for Mr & Mrs Chatham (2023: £410), £2,500 for a restricted fund for Tobermore Football Club (2023: £2,500), £10,000 was held in a Research in PKU fund (2023: nil) and £10,000 was held in a Reaching out fund (2023: nil)

£337,793 (2023: £312,512) was held in the general unrestricted fund and £20,000 (2023: £20,000) was held in a designated grant and research fund.

The society regularly reviews the reserves of the charity by means of the treasurer's report at each meeting, which details all monies held by the charity, including investments and restricted funds. The trustee's policy is to hold reserves to cover a minimum of two year's fixed expenditure which is currently around £140,000 a year.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2024**

**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**Governing document**

The National Society for Phenylketonuria (United Kingdom) Limited is a charitable company limited by guarantee incorporated on 27 April 1976 and registered with the Charity Commission on 16 June 1977.

The charity is controlled by its governing document, Memorandum and Articles of Association dated 27 April 1976, as amended by Special Resolution dated 2 March 1991 and Special Resolution dated 19 March 2011.

**Recruitment and appointment of new trustees**

Vacancies that arise from time to time as determined and agreed by the Council of Management shall be advertised in the Society Magazine and website in the first instance. Applicants will be vetted and appointed by the Trustees and appointees will be made aware of their legal obligations. Training will be given in line with Charity Commission procedures and the Charities SORP (Statement of Operating Recommended Practice). This is a position not to be taken lightly and an honest commitment is required. The same will apply to professionals supporting the society.

**Organisational structure**

The society is controlled by the Council of Management. Trustees during the year are shown in this report. The Council meets bi-monthly, supported by a range of sub-groups. The sub-groups meet to discuss issues at greater length than is possible at Council of Management meetings. All meetings mentioned above have minutes taken. Decisions will be made where possible by consensus; otherwise a majority vote will be used.

**Risk management**

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Registered Company number**

01256124 (England and Wales)

**Registered Charity number**

273670

**Registered office**

St Andrews House  
3 Tarleton Office Park  
Windgate Tarleton  
Preston  
Lancashire  
PR4 6JF

**Trustees**

A Thompson

D Noble- Nesbitt

J Cardy

C Graham (appointed 20.2.24)

S L Noble-Nesbitt (appointed 1.2.24)

J Skidmore (appointed 25.1.24)

K Learoyd

Mrs A Macdonald (appointed 18.5.24)

Dr E Vardy (appointed 18.5.24)

T Chimiak (appointed 18.5.24)

C Cassidy (appointed 18.5.24)

Ms A Bagri (appointed 18.5.24)

**Company Secretary**

K Learoyd

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2024**

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Independent Examiner**

Hayes & Co  
St Andrews House  
3 Tarleton Office Park  
Windgate  
Tarleton  
PR4 6JF

Approved by order of the board of trustees on 21<sup>st</sup> March 2025 and signed on its behalf by:



.....  
A Thompson - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF  
THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**Independent examiner's report to the trustees of The National Society for Phenylketonuria (United Kingdom) Limited ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 October 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**

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.



Anthony N Totham FCA, CTA

Hayes & Co  
St Andrews House  
3 Tarleton Office Park  
Windgate  
Tarleton  
PR4 6JF

Date: .....21/3/25.....

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**STATEMENT OF FINANCIAL ACTIVITIES  
for the year ended 31 October 2024**

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies		109,288	20,000	129,288	100,985
<b>Charitable activities</b>					
Membership and literary fees		16,490	-	16,490	16,297
Conference and events		20,372	-	20,372	5,734
Mr & Mrs Chatham		-	-	-	3,000
Tobermore Football Club		-	-	-	2,500
Vitaflo Sponsorship		18,000	-	18,000	18,000
Investment income	3	11,621	-	11,621	8,183
Other income		<u>6,739</u>	<u>-</u>	<u>6,739</u>	<u>3,366</u>
<b>Total</b>		<u>182,510</u>	<u>20,000</u>	<u>202,510</u>	<u>158,065</u>
<b>EXPENDITURE ON</b>					
<b>Charitable activities</b>					
Conference and events		59,661	-	59,661	-
Publications		18,703	-	18,703	16,514
Research		3,115	-	3,115	21,734
Dietitian's fees and expenses		29,269	-	29,269	25,708
Conference and event costs		-	-	-	14,530
Grants awarded		-	-	-	3,989
Insurance		2,157	-	2,157	2,038
Administration fees and expenses		38,751	7,000	45,751	35,388
Meeting and Conference expenses		167	-	167	1,289
Membership fees and subscriptions		1,747	-	1,747	1,885
Telephone		50	-	50	50
Bank and Other charges		552	-	552	150
Travel		1,230	-	1,230	971
Post, stationery and advertising		1,827	-	1,827	2,345
Depreciation charge		-	2,640	2,640	2,510
NSPKU/ESPKU Subsidy 2023		-	-	-	5,098
NSPKU 2023 50TH Year Celebration costs		-	-	-	1,898
Website costs		<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
<b>Total</b>		<u>157,229</u>	<u>9,640</u>	<u>166,869</u>	<u>136,097</u>
<b>NET INCOME</b>		25,281	10,360	35,641	21,968
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		<u>332,512</u>	<u>34,181</u>	<u>366,693</u>	<u>344,725</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u><u>357,793</u></u>	<u><u>44,541</u></u>	<u><u>402,334</u></u>	<u><u>366,693</u></u>

The notes form part of these financial statements

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**STATEMENT OF FINANCIAL ACTIVITIES  
for the year ended 31 October 2024**

**CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**BALANCE SHEET  
31 October 2024**

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
<b>FIXED ASSETS</b>					
Intangible assets	7	3,686	-	3,686	5,676
<b>CURRENT ASSETS</b>					
Debtors	9	480	-	480	42,285
Prepayments and accrued income		1,306	-	1,306	1,270
Cash at bank		<u>363,563</u>	<u>44,541</u>	<u>408,104</u>	<u>332,067</u>
		365,349	44,541	409,890	375,622
<b>CREDITORS</b>					
Amounts falling due within one year	10	(11,242)	-	(11,242)	(14,605)
<b>NET CURRENT ASSETS</b>		<u>354,107</u>	<u>44,541</u>	<u>398,648</u>	<u>361,017</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>357,793</u>	<u>44,541</u>	<u>402,334</u>	<u>366,693</u>
<b>NET ASSETS</b>		<u>357,793</u>	<u>44,541</u>	<u>402,334</u>	<u>366,693</u>
<b>FUNDS</b>	11				
Unrestricted funds				357,793	332,512
Restricted funds				<u>44,541</u>	<u>34,181</u>
<b>TOTAL FUNDS</b>				<u>402,334</u>	<u>366,693</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 October 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 October 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 NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**BALANCE SHEET - continued  
31 October 2024**

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 21<sup>st</sup> March 2025 and were signed on its behalf by:



.....  
A Thompson - Trustee

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS  
for the year ended 31 October 2024**

**1. ACCOUNTING POLICIES**

**Basis of preparing the financial statements**

The National Society for Phenylketonuria (United Kingdom) Limited is an incorporated charity registered in England. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The registered office address is St Andrews House, 3 Tarleton Office Park, Windgate, Tarleton, Preston, Lancashire, PR4 6JF. The nature of the charity's operations and principal activities are explained in the Trustees report.

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 (FRS102) '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 financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are prepared in sterling which is the functional currency of the charity and rounded to the nearest £.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years.

**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.

Grants are receivable in the SOFA when receivable. When donors specify that grants given to the charity must be used in the future financial years, the income is deferred until that year. Assets and investments donated to the charity are included as donation income at market value at the time of receipt.

No amount is included in the financial statements for volunteer time in line with the SORP (frs 102).

**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.

Charitable expenditure comprises those costs incurred by the charity on delivery of its activities and services, including those costs of any indirect nature necessary to support them.

The charity is not registered for VAT.

**Intangible assets**

Intangible assets are recorded at cost and then amortised on a straight line basis over their useful lives. The useful lives of intangible assets are as follows:

Website - 5 years straight line

Provision is made for any impairment.

**Tangible fixed assets**

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

Computer equipment - 33% on cost

Tangible assets are initially recorded at cost.

**Taxation**

The charity is exempt from corporation tax on its charitable activities.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2024**

**1. ACCOUNTING POLICIES - continued**

**Fund accounting**

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

Designated funds comprise of unrestricted funds that have been set aside by the trustees for particular purposes.

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. The cost of raising and administering such funds are charged against the specific fund.

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

**Going concern**

The trustees assess whether the use of going concern is appropriate i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt on the ability of the charity to continue as a going concern. The trustees make this assessment in respect of a period of at least one year from the date of authorisation for issue of the financial statements and have concluded that the charity has adequate resources to continue in operational existence for the foreseeable future and there are no material uncertainties about the charity's ability to continue as a going concern, thus they continue to adopt the going concern basis of accounting in preparing the financial statements.

**2. CRITICAL ACCOUNTING JUDGEMENTS AND KEY SOURCES OF ESTIMATION  
UNCERTAINTY**

There have been no significant judgements made in the process of preparing the financial statements.

There have been no key assumptions concerning the future and other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

**3. INVESTMENT INCOME**

	2024	2023
	£	£
Deposit account interest	<u>11,621</u>	<u>8,183</u>

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

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

	2024	2023
	£	£
Computer software amortisation	<u>2,640</u>	<u>2,510</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2024**

**5. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 October 2024 nor for the year ended 31 October 2023.

**Trustees' expenses**

There were no trustees' expenses paid for the year ended 31 October 2024 nor for the year ended 31 October 2023.

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	80,985	20,000	100,985
<b>Charitable activities</b>			
Membership and literary fees	16,297	-	16,297
Conference and events	5,734	-	5,734
Mr & Mrs Chatham	-	3,000	3,000
Tobermore Football Club	-	2,500	2,500
Vitaflor Sponsorship	18,000	-	18,000
Investment income	8,183	-	8,183
Other income	<u>3,366</u>	<u>-</u>	<u>3,366</u>
<b>Total</b>	<u>132,565</u>	<u>25,500</u>	<u>158,065</u>
<b>EXPENDITURE ON</b>			
<b>Charitable activities</b>			
Publications	13,924	2,590	16,514
Research	21,734	-	21,734
Dietitian's fees and expenses	23,083	2,625	25,708
Conference and event costs	14,530	-	14,530
Grants awarded	3,989	-	3,989
Insurance	2,038	-	2,038
Administration fees and expenses	32,763	2,625	35,388
Meeting and Conference expenses	1,289	-	1,289
Membership fees and subscriptions	1,885	-	1,885
Telephone	50	-	50
Bank and Other charges	150	-	150
Travel	971	-	971
Post, stationery and advertising	2,345	-	2,345
Depreciation charge	-	2,510	2,510
NSPKU/ESPKU Subsidy 2023	5,098	-	5,098
NSPKU 2023 50TH Year Celebration costs	1,898	-	1,898
Website costs	<u>-</u>	<u>-</u>	<u>-</u>
<b>Total</b>	<u>125,747</u>	<u>10,350</u>	<u>136,097</u>
<b>NET INCOME</b>	6,818	15,150	21,968

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2024**

**6. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued**

	Unrestricted funds £	Restricted funds £	Total funds £
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	325,694	19,031	344,725
	<u>          </u>	<u>          </u>	<u>          </u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u><u>332,512</u></u>	<u><u>34,181</u></u>	<u><u>366,693</u></u>

**7. INTANGIBLE FIXED ASSETS**

	Computer software £
<b>COST</b>	
At 1 November 2023	12,550
Additions	<u>650</u>
At 31 October 2024	<u>13,200</u>
<b>AMORTISATION</b>	
At 1 November 2023	6,874
Charge for year	<u>2,640</u>
At 31 October 2024	<u>9,514</u>
<b>NET BOOK VALUE</b>	
At 31 October 2024	<u><u>3,686</u></u>
At 31 October 2023	<u><u>5,676</u></u>

**8. TANGIBLE FIXED ASSETS**

	Computer equipment £
<b>COST</b>	
At 1 November 2023 and 31 October 2024	<u>430</u>
<b>DEPRECIATION</b>	
At 1 November 2023 and 31 October 2024	<u>430</u>
<b>NET BOOK VALUE</b>	
At 31 October 2024	<u><u>-</u></u>
At 31 October 2023	<u><u>-</u></u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2024**

**9. DEBTORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR**

	2024	2023
	£	£
Trade debtors	<u>480</u>	<u>42,285</u>

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

	2024	2023
	£	£
Trade creditors	9,647	9,505
Accrued expenses	<u>1,595</u>	<u>5,100</u>
	<u>11,242</u>	<u>14,605</u>

**11. MOVEMENT IN FUNDS**

	At 1.11.23 £	Net movement in funds £	At 31.10.24 £
<b>Unrestricted funds</b>			
General fund	312,512	25,281	337,793
NSPKU Grant and research fund	<u>20,000</u>	<u>-</u>	<u>20,000</u>
	332,512	25,281	357,793
<b>Restricted funds</b>			
Research Fund	16,211	-	16,211
Website	15,060	(9,640)	5,420
Mr & Mrs Chatham	410	-	410
Tobermore Football Club	2,500	-	2,500
Research in PKU	-	10,000	10,000
Reaching out fund	<u>-</u>	<u>10,000</u>	<u>10,000</u>
	<u>34,181</u>	<u>10,360</u>	<u>44,541</u>
<b>TOTAL FUNDS</b>	<u>366,693</u>	<u>35,641</u>	<u>402,334</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	182,510	(157,229)	25,281
<b>Restricted funds</b>			
Website	-	(9,640)	(9,640)
Research in PKU	10,000	-	10,000
Reaching out fund	<u>10,000</u>	<u>-</u>	<u>10,000</u>
	<u>20,000</u>	<u>(9,640)</u>	<u>10,360</u>
<b>TOTAL FUNDS</b>	<u>202,510</u>	<u>(166,869)</u>	<u>35,641</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2024**

**11. MOVEMENT IN FUNDS - continued**

**Comparatives for movement in funds**

	At 1.11.22 £	Net movement in funds £	At 31.10.23 £
<b>Unrestricted funds</b>			
General fund	305,694	6,818	312,512
NSPKU Grant and research fund	<u>20,000</u>	<u>-</u>	<u>20,000</u>
	325,694	6,818	332,512
<b>Restricted funds</b>			
Research Fund	16,211	-	16,211
Website	2,820	12,240	15,060
Mr & Mrs Chatham	-	410	410
Tobermore Football Club	<u>-</u>	<u>2,500</u>	<u>2,500</u>
	<u>19,031</u>	<u>15,150</u>	<u>34,181</u>
<b>TOTAL FUNDS</b>	<u><u>344,725</u></u>	<u><u>21,968</u></u>	<u><u>366,693</u></u>

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	132,565	(125,747)	6,818
<b>Restricted funds</b>			
Website	20,000	(7,760)	12,240
Mr & Mrs Chatham	3,000	(2,590)	410
Tobermore Football Club	<u>2,500</u>	<u>-</u>	<u>2,500</u>
	<u>25,500</u>	<u>(10,350)</u>	<u>15,150</u>
<b>TOTAL FUNDS</b>	<u><u>158,065</u></u>	<u><u>(136,097)</u></u>	<u><u>21,968</u></u>

**12. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 31 October 2024.



**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**

England & Wales - Charity number 273670

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# Accounts

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**REGISTERED COMPANY NUMBER: 01256124 (England and Wales)**  
**REGISTERED CHARITY NUMBER: 273670**

**REPORT OF THE TRUSTEES AND**  
**UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 OCTOBER 2023**  
**FOR**  
**THE NATIONAL SOCIETY FOR PHENYLKETONURIA**  
**(UNITED KINGDOM) LIMITED**  
**(A COMPANY LIMITED BY GUARANTEE)**

Hayes & Co  
St Andrews House  
3 Tarleton Office Park  
Windgate  
Tarleton  
PR4 6JF

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COMPANIES HOUSE

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**CONTENTS OF THE FINANCIAL STATEMENTS  
for the year ended 31 October 2023**

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**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED (REGISTERED NUMBER: 01256124)**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2023**

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 31 October 2023, which are prepared to meet the requirements for a directors' report and accounts for Companies Act purposes. 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 to the UK and Republic of Ireland (FRS 102) effective 1 January 2019).

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable in the UK and Republic of Ireland published.

**OBJECTIVES AND ACTIVITIES**

**Objectives and aims**

The objectives of the charity are to promote the educational, medical and social welfare of persons suffering from phenylketonuria and similar disorders controlled by diet, to establish or encourage research in phenylketonuria and related disorders, to establish and maintain a fund or funds from which to make grants for the purpose of fulfilling the objects of the society, to invite, procure, appeal for, collect and receive and accept subscriptions, donations, legacies and gifts of money, investments or other property. The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives, and in planning future objectives.

**Grantmaking policy**

The allocation of grants is decided on an individual basis as an application is made. The application where possible will be discussed by the Council of Management (anonymously if necessary) but if this is not possible a decision will be made by the senior officers and minutes taken at the next Committee of Management meeting. Where applicable, we shall seek guidance from our Medical Advisory Panel.

**Volunteers**

All members of the Council of Management are volunteers. They are encouraged to contribute freely to all discussions and decisions made by the Council. Meetings have minutes taken to reflect discussions, decisions and dissentions.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED (REGISTERED NUMBER: 01256124)**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2023**

**ACHIEVEMENT AND PERFORMANCE**

**Introduction.**

The National Society for Phenylketonuria (NSPKU) has always been at the forefront of supporting individuals and families affected by Phenylketonuria (PKU) through advocacy, awareness, and access to treatment. As we reflect on the past year (and our 50th year!), it is clear that our community's resilience and dedication have been instrumental in moving towards a future where PKU is not a barrier to leading a full and vibrant life.

The year 2023 has been a pivotal and celebratory year for the NSPKU as we marked our 50th anniversary. To mark this significant milestone, we undertook a rebrand of the NSPKU, which has been used extensively throughout the year, heightening awareness of the NSPKU and the work that we do, and providing the charity with a visual presence our community can connect and engage with.

Throughout our Golden Anniversary year, our new branding materials have been embedded within numerous events and campaigns, significantly raising awareness and funds for Phenylketonuria (PKU) support and research.

**Key Achievements of the Year.**

**Fundraising and Community Engagement:** Our community has shown exceptional creativity and commitment through various fundraising activities. Examples include:

\*The Yorkshire Marathon and the art show organized by dedicated members, raising significant funds for NSPKU

\* The innovative London Bridges Walk, which alone raised over £2000

\*The enthusiastic participation in the Epic Liverpool Santa Dash. These events not only raise funds but also crucial awareness within the broader community

\*The fantastic effort of a member running from Great Ormond Street Hospital in London to the Royal Victoria Infirmary in Newcastle. This significant journey was undertaken to raise funds and awareness for NSPKU, highlighting the supportive community and the impactful initiatives carried out by individuals within the PKU community

The NSPKU community has shown remarkable dedication and creativity in raising funds via various events throughout the year, and we cannot thank them enough in supporting our work.

**Advocacy and Access to Treatment:** A significant achievement this year has been our relentless advocacy for equal access to treatments like sapropterin (Kuvan) across the UK. We've seen breakthroughs in Scotland and Northern Ireland, thanks to the collective efforts of our community and supportive policymakers, and our participation in governmental discussions and public awareness campaigns has elevated the visibility of PKU challenges and treatments.

**Support and Information Services:** Our support services have been a lifeline for many families. From providing updated dietary guidelines to hosting educational webinars, we've ensured that our community remains informed and supported. The feedback has been overwhelmingly positive, highlighting the value of these resources. NSPKU provided extensive support to families affected by PKU, offering resources, guidance, and direct assistance to improve their daily management of the condition via our telephone support line.

**Research and Partnerships:** The NSPKU has continued to support and fund research aimed at improving the lives of those affected by PKU. This includes partnerships with medical researchers and institutions to advance understanding of the disease and develop new treatments. The NSPKU has actively participated in research initiatives, aiming to bring innovative treatments and improve the quality of life for those affected by PKU.

**Annual trip to Edale:** The trip to Edale involved a weekend of activities aimed at children with PKU and their families. This event, known as the Edale Activity Weekend, was highlighted by Captain PHELIX, our beloved mascot who oversees our NSPKU events and activities. It provided an opportunity for children with PKU to engage in various outdoor activities, fostering community ties and allowing them to experience adventures that are both fun and inclusive. The event was well-received, contributing to the children's social interactions and their families' connections within the PKU community.

**Golden Anniversary events and celebrations:** We produced a special edition newsletter focusing on our 50th Anniversary was released, celebrating the progress and impact of NSPKU over the years, and a display of art created by the children and young people within our community to celebrate this milestone. We also planned and held a wide variety of events throughout 2023 included collaborations with local groups with an emphasis on community engagement, with events like the ESPKU conference and House of Lords reception highlighted as major milestones. These events not only marked the milestone anniversary but also showcased the continued effort of NSPKU to engage with and support the PKU community through comprehensive programs and celebrations.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED (REGISTERED NUMBER: 01256124)**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2023**

**House of Lords Reception:** The House of Lords reception was a significant highlight of the year, where key issues related to PKU were addressed at a high level. The event facilitated valuable discussions among stakeholders about the challenges and needs of the PKU community, including access to treatments and support for individuals and families affected by PKU. This represents an important step in raising awareness and seeking policy changes to improve the lives of those living with PKU.

**ESPKU Conference:** The ESPKU Conference held in Birmingham was a highlight of the year, where discussions on unequal PKU treatment across Europe and presentations on new research, such as synthetic probiotics for PKU, were key topics. The NSPKU enabled a number of families and members of the charity to attend and contribute to the discussions taking place.

**Challenges and Opportunities.**

While we have made significant strides, challenges remain. Access to new and existing treatments varies across different regions, and dietary management continues to be a significant burden for many families. The upcoming year will focus on reducing these disparities and advocating for broader access to PKU treatments. Efforts to enhance public understanding of PKU through education, media engagements, and community programs have been pivotal and will continue as a major focus in the future.

**Looking Ahead.**

As we move into the next year, our goals are clear:

- \*To enhance our advocacy efforts to ensure that all PKU patients in the UK have access to the best possible care
- \* To expand our support services to include more personalised assistance and to reach underserved areas
- \*To foster stronger relationships with international PKU organisations, sharing knowledge and resources to better serve our communities
- \* To continue to support Research and Development - The NSPKU has actively participated in research initiatives, aiming to bring innovative treatments and improve the quality of life for those affected by PKU - this will remain a key focus

**Conclusion.**

The achievements of the past year reflect the strength and dedication of the PKU community. We are eternally grateful for the hard work of our volunteers, the generosity of our donors, and the guidance of our Council of Management. Together, we are making a significant impact on the lives of those affected by PKU. We look forward to another year of progress and positive change.

We extend our deepest thanks to all our supporters, volunteers, staff, and trustees for their unwavering commitment and enthusiasm. Your contributions drive the success of our mission and the well-being of the PKU community.

**FINANCIAL REVIEW**

**Financial position**

The net incoming resources for the year were £ 21,968 ( 2022: £21,680, details of which are shown on the statement of Financial Activities.

**Principal funding sources**

The principal funding sources are donations, sponsorships and fund raising activities and are shown in the Statement of Financial Activities and in the notes to the accounts.

**Investment policy and objectives**

The society's policy is to hold surplus funds in building society and deposit accounts.

**Reserves policy**

At 31 October 2023 £16,211 ( 2022:£16,211) was held in the restricted research fund, £2,820 was held in a restricted fund for a new website ( 2022:£2,820), £410 was held in a restricted fund for Mr & Mrs Chatham ( 2022: nil) and £2,500 for a restricted fund for Tobermore Football Club (2022: nil).

£312,512 (2022: £305,965) was held in the general unrestricted fund and £20,000 ( 2022: £20,000) was held in a designated grant and research fund.

The society regularly reviews the reserves of the charity by means of the treasurer's report at each meeting, which details all monies held by the charity, including investments and restricted funds. The trustee's policy is to hold reserves to cover a minimum of two year's fixed expenditure which is currently around £140,000 a year.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED (REGISTERED NUMBER: 01256124)**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2023**

**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**Governing document**

The National Society for Phenylketonuria (United Kingdom) Limited is a charitable company limited by guarantee incorporated on 27 April 1976 and registered with the Charity Commission on 16 June 1977.

The charity is controlled by its governing document, Memorandum and Articles of Association dated 27 April 1976, as amended by Special Resolution dated 2 March 1991 and Special Resolution dated 19 March 2011.

**Recruitment and appointment of new trustees**

Vacancies that arise from time to time as determined and agreed by the Council of Management shall be advertised in the Society Magazine and website in the first instance. Applicants will be vetted and appointed by the Senior Officers and appointees will be made aware of their legal obligations. Training will be given in line with Charity Commission procedures and the Charities SORP (Statement of Operating Recommended Practice). This is a position not to be taken lightly and an honest commitment is required. The same will apply to professionals supporting the society.

**Organisational structure**

The society is controlled by the Council of Management. Trustees during the year are shown in this report. The Council meets at least four times a year and the senior officers meet separately up to twice a year.

The senior officers meet to discuss issues at greater length than is possible at Council of Management meetings. This allows them to define the society's policy proposals for discussion of the Council of Management.

All meetings mentioned above have minutes taken. Decisions will be made where possible by consensus; otherwise a majority vote will be used.

**Risk management**

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Registered Company number**

01256124 (England and Wales)

**Registered Charity number**

273670

**Registered office**

St Andrews House  
3 Tarleton Office Park  
Windgate Tarleton  
Preston  
Lancashire  
PR4 6JF

**Principal address**

NSPKU  
PO Box 6046  
Sheffield  
S12 9ET

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED (REGISTERED NUMBER: 01256124)**

**REPORT OF THE TRUSTEES  
for the year ended 31 October 2023**

**Trustees**

E W Lange (resigned 21.10.23)  
A Thompson  
I Williamson (resigned 21.10.23)  
D Noble- Nesbitt  
J Cardy  
C Graham (appointed 20.2.24)  
S L Noble-Nesbitt (appointed 1.2.24)  
J Skidmore (appointed 25.1.24)  
K Learoyd (appointed 12.11.23)  
Mrs A Macdonald (appointed 18.5.24)  
Dr E Vardy (appointed 18.5.24)  
T Chimiak (appointed 18.5.24)  
C Cassidy (appointed 18.5.24)  
Ms A Bagri (appointed 18.5.24)

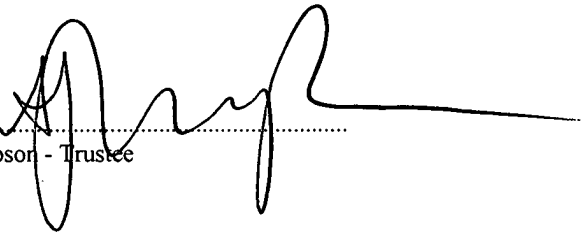
**Company Secretary**

K Learoyd

**Independent Examiner**

Hayes & Co  
St Andrews House  
3 Tarleton Office Park  
Windgate  
Tarleton  
PR4 6JF

Approved by order of the board of trustees on 18/5/2024 and signed on its behalf by:

  
.....  
A Thompson - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF  
THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**Independent examiner's report to the trustees of The National Society for Phenylketonuria (United Kingdom) Limited ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 October 2023.

**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**

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.



Anthony N Totham FCA, CTA

Hayes & Co  
St Andrews House  
3 Tarleton Office Park  
Windgate  
Tarleton  
PR4 6JF

Date: .....18/10/24.....

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**STATEMENT OF FINANCIAL ACTIVITIES  
for the year ended 31 October 2023**

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies		80,985	20,000	100,985	64,809
<b>Charitable activities</b>					
National Lottery Grant		-	-	-	10,000
Membership and literary fees		16,297	-	16,297	16,397
Conference and events		5,734	-	5,734	29,705
Mr & Mrs Chatham		-	3,000	3,000	-
Tobermore Football Club		-	-	-	-
Vitaflo Sponsorship		18,000	2,500	18,000	-
Investment income	3	8,183	-	8,183	1,338
Other income		3,366	-	3,366	14,400
<b>Total</b>		<b>132,565</b>	<b>25,500</b>	<b>158,065</b>	<b>136,649</b>
<b>EXPENDITURE ON</b>					
<b>Charitable activities</b>					
Publications		13,924	2,590	16,514	14,070
Research		21,734	-	21,734	2,880
Dietitian's fees and expenses		23,083	2,625	25,708	22,183
Conference and event costs		14,530	-	14,530	41,273
Grants awarded		3,989	-	3,989	2,608
Sponsorship		-	-	-	444
Insurance		2,038	-	2,038	2,341
Administration fees and expenses		32,763	2,625	35,388	19,650
Meeting and Conference expenses		1,289	-	1,289	876
Membership fees and subscriptions		1,885	-	1,885	1,137
Telephone		50	-	50	150
Bank and Other charges		150	-	150	737
Travel		971	-	971	164
Post,stationery and advertising		2,345	-	2,345	2,602
Depreciation charge		-	2,510	2,510	1,866
Examination fees		-	-	-	1,988
NSPKU/ESPKU Subsidy 2023		5,098	-	5,098	-
NSPKU 2023 50TH Year Celebration costs		-	-	-	-
Website costs		1,898	-	1,898	-
<b>Total</b>		<b>125,747</b>	<b>10,350</b>	<b>136,097</b>	<b>114,969</b>
<b>NET INCOME</b>		<b>6,818</b>	<b>15,150</b>	<b>21,968</b>	<b>21,680</b>
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		325,694	19,031	344,725	323,045

The notes form part of these financial statements

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**STATEMENT OF FINANCIAL ACTIVITIES  
for the year ended 31 October 2023**

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u>332,512</u>	<u>34,181</u>	<u>366,693</u>	<u>344,725</u>

**CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED (REGISTERED NUMBER: 01256124)**

**BALANCE SHEET  
31 October 2023**

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
<b>FIXED ASSETS</b>					
Intangible assets	7	5,676	-	5,676	4,964
<b>CURRENT ASSETS</b>					
Debtors	9	42,285	-	42,285	17,793
Prepayments and accrued income		1,270	-	1,270	5,513
Cash at bank		297,886	34,181	332,067	323,970
		<u>341,441</u>	<u>34,181</u>	<u>375,622</u>	<u>347,276</u>
<b>CREDITORS</b>					
Amounts falling due within one year	10	(14,605)	-	(14,605)	(7,515)
<b>NET CURRENT ASSETS</b>					
		<u>326,836</u>	<u>34,181</u>	<u>361,017</u>	<u>339,761</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>					
		<u>332,512</u>	<u>34,181</u>	<u>366,693</u>	<u>344,725</u>
<b>NET ASSETS</b>					
		<u><u>332,512</u></u>	<u><u>34,181</u></u>	<u><u>366,693</u></u>	<u><u>344,725</u></u>
<b>FUNDS</b>					
Unrestricted funds	11			332,512	325,694
Restricted funds				34,181	19,031
<b>TOTAL FUNDS</b>					
				<u><u>366,693</u></u>	<u><u>344,725</u></u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 October 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 October 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

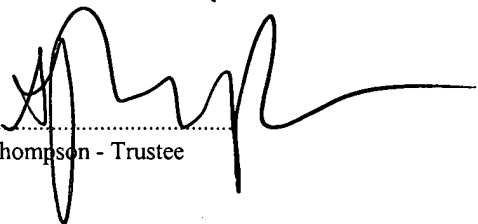
- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its 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 NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED (REGISTERED NUMBER: 01256124)**

**BALANCE SHEET - continued  
31 October 2023**

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  
18/11/2024 and were signed on its behalf by:

  
.....  
A Thompson - Trustee

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS  
for the year ended 31 October 2023**

**1. ACCOUNTING POLICIES**

**Basis of preparing the financial statements**

The National Society for Phenylketonuria (United Kingdom) Limited is an incorporated charity registered in England. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The registered office address is St Andrews House, 3 Tarleton Office Park, Windgate, Tarleton, Preston, Lancashire, PR4 6JF. The nature of the charity's operations and principal activities are explained in the Trustees report.

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 (FRS102) '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 financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are prepared in sterling which is the functional currency of the charity and rounded to the nearest £.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years.

**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.

Grants are receivable in the SOFA when receivable. When donors specify that grants given to the charity must be used in the future financial years, the income is deferred until that year. Assets and investments donated to the charity are included as donation income at market value at the time of receipt.

No amount is included in the financial statements for volunteer time in line with the SORP (FRS 102).

**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.

Charitable expenditure comprises those costs incurred by the charity on delivery of its activities and services, including those costs of any indirect nature necessary to support them.

The charity is not registered for VAT.

**Intangible assets**

Intangible assets are recorded at cost and then amortised on a straight line basis over their useful lives. The useful lives of intangible assets are as follows:

Website - 5 years straight line

Provision is made for any impairment.

**Tangible fixed assets**

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

Computer equipment - 33% on cost

Tangible assets are initially recorded at cost.

**Taxation**

The charity is exempt from corporation tax on its charitable activities.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2023**

**1. ACCOUNTING POLICIES - continued**

**Fund accounting**

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

Designated funds comprise of unrestricted funds that have been set aside by the trustees for particular purposes.

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. The cost of raising and administering such funds are charged against the specific fund.

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

**Going concern**

The trustees assess whether the use of going concern is appropriate i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt on the ability of the charity to continue as a going concern. The trustees make this assessment in respect of a period of at least one year from the date of authorisation for issue of the financial statements and have concluded that the charity has adequate resources to continue in operational existence for the foreseeable future and there are no material uncertainties about the charity's ability to continue as a going concern, thus they continue to adopt the going concern basis of accounting in preparing the financial statements.

**2. CRITICAL ACCOUNTING JUDGEMENTS AND KEY SOURCES OF ESTIMATION UNCERTAINTY**

There have been no significant judgements made in the process of preparing the financial statements.

There have been no key assumptions concerning the future and other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

**3. INVESTMENT INCOME**

	2023	2022
	£	£
Deposit account interest	8,183	1,338

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

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

	2023	2022
	£	£
Depreciation - owned assets	-	430
Computer software amortisation	2,510	1,866

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2023**

**5. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 October 2023 nor for the year ended 31 October 2022.

**Trustees' expenses**

There were no trustees' expenses paid for the year ended 31 October 2023 nor for the year ended 31 October 2022.

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	64,809	-	64,809
<b>Charitable activities</b>			
National Lottery Grant	-	10,000	10,000
Membership and literary fees	16,397	-	16,397
Conference and events	29,705	-	29,705
Investment income	1,338	-	1,338
Other income	14,400	-	14,400
<b>Total</b>	<u>126,649</u>	<u>10,000</u>	<u>136,649</u>
<b>EXPENDITURE ON</b>			
<b>Charitable activities</b>			
Publications	14,070	-	14,070
Research	2,880	-	2,880
Dietitian's fees and expenses	22,183	-	22,183
Conference and event costs	31,273	10,000	41,273
Grants awarded	2,608	-	2,608
Sponsorship	444	-	444
Insurance	2,341	-	2,341
Administration fees and expenses	19,650	-	19,650
Meeting and Conference expenses	876	-	876
Membership fees and subscriptions	1,137	-	1,137
Telephone	150	-	150
Bank and Other charges	737	-	737
Travel	164	-	164
Post, stationery and advertising	2,602	-	2,602
Depreciation charge	1,866	-	1,866
Examination fees	1,988	-	1,988
<b>Total</b>	<u>104,969</u>	<u>10,000</u>	<u>114,969</u>
<b>NET INCOME</b>	21,680	-	21,680
<b>Transfers between funds</b>	1,834	(1,834)	-
<b>Net movement in funds</b>	23,514	(1,834)	21,680
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	302,180	20,865	323,045

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2023**

**6. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued**

	Unrestricted funds £	Restricted funds £	Total funds £
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u>325,694</u>	<u>19,031</u>	<u>344,725</u>

**7. INTANGIBLE FIXED ASSETS**

	Computer software £
<b>COST</b>	
At 1 November 2022	9,328
Additions	3,222
At 31 October 2023	<u>12,550</u>
<b>AMORTISATION</b>	
At 1 November 2022	4,364
Charge for year	2,510
At 31 October 2023	<u>6,874</u>
<b>NET BOOK VALUE</b>	
At 31 October 2023	<u>5,676</u>
At 31 October 2022	<u>4,964</u>

**8. TANGIBLE FIXED ASSETS**

	Computer equipment £
<b>COST</b>	
At 1 November 2022 and 31 October 2023	430
<b>DEPRECIATION</b>	
At 1 November 2022 and 31 October 2023	430
<b>NET BOOK VALUE</b>	
At 31 October 2023	<u>-</u>
At 31 October 2022	<u>-</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2023**

**9. DEBTORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR**

	2023	2022
	£	£
Trade debtors	42,285	17,793

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

	2023	2022
	£	£
Trade creditors	9,505	6,084
Accrued expenses	5,100	1,431

**11. MOVEMENT IN FUNDS**

	At 1.11.22 £	Net movement in funds £	At 31.10.23 £
<b>Unrestricted funds</b>			
General fund	305,694	6,818	312,512
NSPKU Grant and research fund	20,000	-	20,000
	<u>325,694</u>	<u>6,818</u>	<u>332,512</u>
<b>Restricted funds</b>			
Research Fund	16,211	-	16,211
Website	2,820	12,240	15,060
Mr & Mrs Chatham	-	410	410
Tobermore Football Club	-	2,500	2,500
	<u>19,031</u>	<u>15,150</u>	<u>34,181</u>
<b>TOTAL FUNDS</b>	<u>344,725</u>	<u>21,968</u>	<u>366,693</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	132,565	(125,747)	6,818
<b>Restricted funds</b>			
Website	20,000	(7,760)	12,240
Mr & Mrs Chatham	3,000	(2,590)	410
Tobermore Football Club	2,500	-	2,500
	<u>25,500</u>	<u>(10,350)</u>	<u>15,150</u>
<b>TOTAL FUNDS</b>	<u>158,065</u>	<u>(136,097)</u>	<u>21,968</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA  
(UNITED KINGDOM) LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
for the year ended 31 October 2023**

**11. MOVEMENT IN FUNDS - continued**

**Comparatives for movement in funds**

	At 1.11.21 £	Net movement in funds £	Transfers between funds £	At 31.10.22 £
<b>Unrestricted funds</b>				
General fund	282,180	21,680	1,834	305,694
NSPKU Grant and research fund	20,000	-	-	20,000
	<u>302,180</u>	<u>21,680</u>	<u>1,834</u>	<u>325,694</u>
<b>Restricted funds</b>				
Research Fund	16,211	-	-	16,211
Website	4,654	-	(1,834)	2,820
	<u>20,865</u>	<u>-</u>	<u>(1,834)</u>	<u>19,031</u>
<b>TOTAL FUNDS</b>	<u><u>323,045</u></u>	<u><u>21,680</u></u>	<u><u>-</u></u>	<u><u>344,725</u></u>

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	126,649	(104,969)	21,680
<b>Restricted funds</b>			
Conference	10,000	(10,000)	-
<b>TOTAL FUNDS</b>	<u><u>136,649</u></u>	<u><u>(114,969)</u></u>	<u><u>21,680</u></u>

**12. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 31 October 2023.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**

England & Wales - Charity number 273670

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# Accounts

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Company No. 01256124

Charity No. 273670

**The National Society  
for Phenylketonuria  
(United Kingdom)  
Limited**

**(A registered charity and company  
limited by guarantee)**

**Report and Financial Statements**

**For The Year Ended  
31 October 2021**

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

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Balance sheet	8
Notes to the accounts	9

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# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## CHARITY INFORMATION

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<b>Trustees/Directors/Council of Management:</b>	E W Lange A Thompson I E Williamson D Noble-Nesbit J Cardy L Lee	Chair Treasurer (appointed 29/02/20) Honorary Secretary
<b>Company Secretary:</b>	I E Williamson	
<b>Registered office:</b>	Richard House Winckley Square Preston PR1 3HP	
<b>Contact address:</b>	NSPKU PO Box 3143 Purley CR8 9DD	
<b>Company Number:</b>	01256124	
<b>Charity Number:</b>	273670	
<b>Independent examiner:</b>	Mrs N Mason FCA, DChA MHA Moore and Smalley Richard House Winckley Square Preston PR1 3HP	
<b>Bankers:</b>	HSBC 49a Fishergate Preston PR1 8BQ	
	CCLA Investment Management Ltd COIF Charity Funds 80 Cheapside London EC2V 6DZ	
	The Affirmative Deposit Fund for Charities Central Finance Board 9 Bonhill Street London EC2A 4 PE	
	Leeds Building Society 105 Albion Street Leeds LS1 5AS	
<b>Website:</b>	<a href="http://www.nspku.org">www.nspku.org</a>	
<b>Email:</b>	<a href="mailto:info@nspku.org">info@nspku.org</a>	

# **THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**

## **TRUSTEES' REPORT**

**FOR THE YEAR ENDED 31 OCTOBER 2021**

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The trustees of The National Society for Phenylketonuria (United Kingdom) Limited who are also the directors for the purposes of the Companies Act, present their annual report and the financial statements for the year ended 31 October 2021, which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" (FRS 102) in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and 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 published October 2019.

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

#### **Governing document**

NSPKU is a charitable company limited by guarantee incorporated on 27 April 1976 and registered with the Charity Commission on 16 June 1977.

The charity is controlled by its governing document, Memorandum and Articles of Association dated 27 April 1976, as amended by Special Resolution dated 2 March 1991 and Special Resolution dated 19 March 2011.

#### **Recruitment, appointment, induction and training of new trustees**

Vacancies that arise from time to time as determined and agreed by the Council of Management shall be advertised in the Society Magazine and website in the first instance. Applicants will be vetted and appointed by the Senior Officers and appointees will be made aware of their legal obligations. Training will be given in line with Charity Commission procedures and the Charities SORP (Statement of Operating Recommended Practice). This is a position not to be taken lightly and an honest commitment is required. The same will apply to professionals supporting the society.

#### **Organisational structure**

The society is controlled by the Council of Management. Trustees during the year are shown on page 1. The Council meets at least four times a year and the senior officers meet separately up to twice a year.

The senior officers meet to discuss issues at greater length than is possible at Council of Management meetings. This allows them to define NSPKU policy proposals for discussion of the Council of Management.

All meetings mentioned above have minutes taken. Decisions will be made where possible by consensus; otherwise a majority vote will be used.

#### **Risk management**

The trustees have a duty to identify the risks to which the charity is exposed and have reviewed the risks and established appropriate systems or procedures to mitigate those risks.

### **OBJECTIVES AND ACTIVITIES:**

#### **Objectives and activities for the public benefit**

The objectives of the charity are to promote the educational, medical and social welfare of persons suffering from phenylketonuria and similar disorders controlled by diet, to establish or encourage research in phenylketonuria and related disorders, to establish and maintain a fund or funds from which to make grants for

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## TRUSTEES' REPORT

FOR THE YEAR ENDED 31 OCTOBER 2021

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### Objectives and activities for the public benefit (continued)

the purpose of fulfilling the objects of the society, to invite, procure, appeal for, collect and receive and accept subscriptions, donations, legacies and gifts of money, investments or other property. The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives, and in planning future objectives.

### Grant making policy

The allocation of grants is decided on an individual basis as an application is made. The application where possible will be discussed by the Council of Management (anonymously if necessary) but if this is not possible a decision will be made by the senior officers and minutes taken at the next Committee of Management meeting. Where applicable, we shall seek guidance from our Medical Advisory Panel.

### Volunteers

All members of the Council of Management are volunteers. They are encouraged to contribute freely to all discussions and decisions made by the Council. Meetings have minutes taken to reflect discussions, decisions and dissensions.

### ACHIEVEMENT AND PERFORMANCE:

The Financial Year ended 31<sup>st</sup> October 2021 was again impacted by Covid. We were unable to have a face-to-face conference as in prior years. However, we organised a number of online events that were very well attended. Captain Phenix- our new mascot- made his debut. Edale went ahead this year , however Keswick had to be cancelled. A year does not go by with out a survey. This year we had two (1) a survey for parents with children under 18 asking them about their experiences with clinical services in Children's Hospitals and (2) a survey for adult patients over 18 asking them what they had experienced in metabolic clinics and what they expected. Both were well received and completed by many members and non-members for which we are grateful.

During the year a number of publications – including updates to old ones – were drafted by a team of dedicated dietitians who met every Friday. Many of these have now been published on the website. Resulting downloads suggested these were much needed. Also, we re-established sending out hard copies of News and Views which was welcome by all. Towards the end of the year , we placed a new order for the new parent wallets which have been a great success with families with PKU babies.

We looked at the possibility of funding some further research. Topics looked at were – returning to diet , maternal PKU pre and post conception, and looking at the outcomes of patients over 50. The decision was deferred until the next financial year primarily due to a drop off in income.

On the advocacy front: the PKU APPG met in November 2020 to discuss a variety of topics including the use of Sapropterin in maternal PKU, the effect of Brexit, Covid and the sugar tax. The National Institute of Clinical Excellence ( NICE ) published a recommendation in February 2021 for Sapropterin for children up to the age of 18. We held an online meeting with members about this before the April NICE Meeting. Many of our members and supporters made submissions during the consultation period. We have it on good authority that they had never been so busy during this timeframe. In their final recommendation, they recommended to NHS England that up to 10 mg for children up to the age of 18 and or use in pregnancy should be funded. In our opinion, this undervalued major issues for adults with PKU and was not acceptable.

Although things went quiet to the end of the financial year , there was a lot of work going on in the background. In particular at the end of the year , it was announced that a generic form of Sapropterin had been approved by the Medicines & Healthcare products Regulatory Agency ( MHRA). This led to NHS England approving the generic for all PKU patients that were responders. Loading tests on patients began in time for Christmas 2021. We are now seeking the same level of commitment from the Health Services in the rest of the United Kingdom.

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## TRUSTEES' REPORT

### FOR THE YEAR ENDED 31 OCTOBER 2021

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This has been a “long march” for PKU patients having access to a drug which is widely used elsewhere in Europe. We owe much to our advocacy team for spearheading this. We must not forget all our members, parliamentarians, consultants, and dietitians who supported us along the way. Well done to all and especially to Kate Learoyd and Caroline Graham whose indefatigability has seen us through.

We have held seven Council of Management (COM) meetings during the year. In each meeting we review phone and email helpline logs. This enables us to establish what issues our membership are encountering in everyday life. Alas, each year throws up a challenge beyond our remit. In some cases we have to initiate multi-disciplinary actions to see a PKU patient and/or family through difficult times. Unfortunately, we do not see this abating any time soon. We have to be alert to these situations and act fast as we can. Currently, we believe we have the mechanisms in place to do this.

We also monitor the number of requests for help with PIP and DLA. These seem to have increased during the year. The good news appears to be that more members are getting accepted (at various levels). We are striving to get PKU recognised in the DWP rulebook. This would ease the burden on the NSPKU and patients applying.

Also, it has been noted that more and more PKU Adults are returning to diet. This is a very encouraging trend – especially when those returning to diet feel the benefits.

In May, the TV programme “Call the Midwife” briefly touched on PKU – all too briefly. The positive outcome from this, is it gave exposure to PKU. We had an online event to discuss this and late treated PKU. A most welcome discussion.

International PKU Day saw the NSPKU and its supporters “Go Green for PKU”. There were green goody bags for the first 100 members who applied. There were many schools and nurseries who helped raise awareness of PKU. We held a virtual meeting with some first-class discussions and a tribute to Dr John Nobel-Nesbitt who passed away but gave so much to the NSPKU and formalised the Medical Advisory Panel.

The Medical Advisory Panel (MAP) met twice during the year where we were updated about the Birmingham “app” called PKU Bite. This has been trialled and tested and has earned the nickname “the dietitian in my pocket”. The full roll out will be in the next financial year. Genotyping is another hot topic discussed. This is carried out in Scotland at birth. It is not done automatically elsewhere in the UK. However, the conversation is changing – in particular with the introduction of Sapropterin to establish who will be a responder. Large neutral amino acids (LNAAs) were discussed, and we have suggested these could be another string to adult consultants in helping PKU adults cope with their diet.

#### **The Year Ahead**

We shall continue with online meetings until we are able to meet face-to-face again. We are organising a Conference in late September 2022 at a Hotel in Brigg, North Lincolnshire. Due to the lateness of this, we shall not have one in Spring 2023 as we are hosting the ESPKU Conference in October. We shall be planning next year for 2023 day events for members in Northern Ireland, England, Wales and Scotland.

2023 will see the Society's 50<sup>th</sup> Anniversary. We feel a lot of preparation needs to be done for this and we have already begun planning for it. We are looking to have a revised logo and branding for this. This may also be a good opportunity to rebrand the Society as a whole and discussions will be held mid 2022 on this topic. We expect that Edale will go ahead in 2022, but Keswick hangs in the balance.

Our meetings with MAP have traditionally been on a bi-annual basis. However, due to issues with the protocol for Sapropterin testing, and its roll-out, we have started to have more regular meetings. One of the major issues that keeps cropping up is food labelling. This is always an issue for PKU patients. Expect much work in this area in the future.

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## TRUSTEES' REPORT

FOR THE YEAR ENDED 31 OCTOBER 2021

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### The Year Ahead (Continued)

Of vital importance is the PKU network within the UK. We aim to foster support groups throughout the country. If you wish to start one, please get in touch at [info@nspku.org](mailto:info@nspku.org).

We extend our gratitude to all our support staff for all their hard work for the year Administrator Alison Green, Bookkeeper Margaret Butcher and of course our Society Dietitian Suzanne Ford.

To all our members and the wider PKU Community a sincere thank you to all for your contributions to the NSPKU – be they financial or otherwise. We extend our gratitude to the Daily Express who have championed our cause since 2019.

### FINANCIAL REVIEW:

The net incoming resources for the year were £10,250 (2020: (£24,031)), details of which are shown on the Statement of Financial Activities.

### Reserves policy

At 31 October 2021 £16,211 (2020: £16,211) was held in the restricted research fund, £4,654 was held in a restricted fund for the new website (2020: £4,654), £282,180 (2020: £271,930) was held in the general unrestricted fund and £20,000 (2020: £20,000) was held in a designated grant and research fund. £297,185 (2020: £266,245) are free reserves.

The society regularly reviews the reserves of the charity by means of the treasurer's report at each meeting, which details all monies held by the charity, including investments and restricted funds. The trustees' policy is to hold reserves to cover a minimum of two year's fixed expenditure which is currently around £180,000 year. Free reserves are to be used to fund new activities in the future.

Sources of funding are shown in the Statement of Financial Activities and in the notes to the accounts.

### Investment policy and objectives

The society's policy is to hold surplus funds in building society and deposit accounts.

### Small company provisions

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

This report was approved by the trustees on 27/07/2022.....and signed on their behalf by:

*Eric Lange*

.....

**E W Lange – Chair**

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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I report to the charity trustees on my examination of the accounts of the company for the year ended 31 October 2021 which are set out on pages 7 to 18.

**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**

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 in any material respect:

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;
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 the report in order to enable a proper understanding of the account to be reached.

*Nicola Mason*

**N Mason FCA, DChA**  
**MHA Moore and Smalley**  
**Chartered Accountants**  
**Preston**

Date 28/07/2022.....

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**STATEMENT OF FINANCIAL ACTIVITIES (INC INCOME AND EXPENDITURE ACCOUNT)**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

Income	Note	Unrestricted funds £	Restricted funds £	Total funds 2021 £	Total funds 2020 £
Donations, grants and legacies	2	66,088	-	66,088	77,966
Income from charitable activities	3	18,780	-	18,780	25,235
Income from other trading activities	4	5,100	-	5,100	13,372
Investment income	5	92	-	92	1,064
<b>Total income</b>		<b>90,060</b>	<b>-</b>	<b>90,060</b>	<b>117,637</b>
<b>Resources expended</b>					
<i>Costs of raising funds:</i>					
Fundraising trading: cost of goods sold and other costs		-	-	-	3,016
Charitable activities	6	79,810	-	79,810	90,590
<b>Total expenditure</b>		<b>79,810</b>	<b>-</b>	<b>79,810</b>	<b>93,606</b>
<b>Net income/(expenditure) for the year</b>		<b>10,250</b>	<b>-</b>	<b>10,250</b>	<b>24,031</b>
Transfers between funds		-	-	-	-
<b>Net movement in funds</b>		<b>10,250</b>	<b>-</b>	<b>10,250</b>	<b>24,031</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		291,930	20,865	312,795	288,764
<b>Total funds carried forward</b>		<b>302,180</b>	<b>20,865</b>	<b>323,045</b>	<b>312,795</b>

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing activities. The notes on pages 9 to 18 form part of these accounts.

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## BALANCE SHEET

AS AT 31 OCTOBER 2021

	Note	Unrestricted funds £	Restricted funds £	Total funds 2021	Total funds 2020 £
<b>Fixed assets</b>					
Intangible assets	8	4,996	-	4,996	6,495
Tangible assets	9	-	-	-	-
		4,996	-	4,996	6,495
<b>Current assets</b>					
Debtors	11	4,539	-	4,539	2,708
Cash at bank and in hand		295,793	20,865	316,658	308,040
		300,332	20,865	321,197	310,748
<b>Creditors: Amounts falling due within one year</b>	12	(3,147)	-	(3,147)	(4,448)
<b>Net current assets</b>		297,185	20,865	318,105	306,300
<b>Net assets</b>		302,180	20,865	323,045	312,795
<b>Funds</b>					
	13				
Unrestricted – general		282,180	-	282,180	271,930
Unrestricted -designated		20,000	-	20,000	20,000
Restricted			20,865	20,865	20,865
<b>Total funds</b>		302,180	20,865	323,045	312,795

For the year ending 31 October 2021 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

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

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

These financial statements were approved by the trustees and authorised for issue on 27/07/2022 and are signed on their behalf by:

*Eric Lange*

.....  
E W Lange - Chair  
Company number: 01256124



.....  
I Williamson – Secretary

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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**1 Accounting policies**

**Basis of preparation**

The National Society for Phenylketonuria (United Kingdom) Limited is an incorporated charity registered in England. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are explained in the Trustees Report.

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with 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) issued on October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are prepared in sterling which is the functional currency of the and rounded to the nearest £.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years.

**Going concern**

The trustees assess whether the use of going concern is appropriate i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt on the ability of the company to continue as a going concern. The trustees make this assessment in respect of a period of at least one year from the date of authorisation for issue of the financial statements and have concluded that the charity has adequate resources to continue in operational existence for the foreseeable future and there are no material uncertainties about the charity's ability to continue as a going concern, thus they continue to adopt the going concern basis of accounting in preparing the financial statements.

**Incoming resources**

All incoming resources are included on the Statement of Financial Activities when the charity is legally entitled to the income, the amount can be quantified with reasonable accuracy and it is probable that the income will be received.

Grants are recognised in the SOFA when receivable. When donors specify that grants given to the charity must be used in the future financial years, the income is deferred until that year. Assets and investments donated to the charity are included as donation income at market value at the time of the receipt.

No amount is included in the financial statements for volunteer time in line with the SORP (FRS 102).

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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**1 Accounting policies (continued)**

**Resources expended**

The charity is not registered for VAT. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs 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.

Charitable expenditure comprises those costs incurred by the charity on delivery of its activities and services, including those costs of any indirect nature necessary to support them.

**Taxation**

As a registered charity, the society is exempt from corporation tax on its charitable activities to the extent that these are applied to its charitable objects.

**Intangible assets**

Intangible assets are amortised on a straight-line basis over their useful lives. The useful lives of intangible assets are as follows:

Website - 5 years straight line

Provision is made for any impairment.

**Fixed assets**

Tangible fixed assets are stated at cost less accumulated depreciation. Cost includes costs directly attributable to making the asset capable of operating as intended.

Depreciation is provided on all tangible fixed assets, at rates calculated to write off the cost, less estimated residual value, of each asset on a systematic basis over its expected useful life as follows:

Computer equipment - 33% on cost

**Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Designated funds comprise unrestricted funds that have been set aside by the trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the financial statements.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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**1 Accounting policies (continued)**

**Judgements and key sources of estimation uncertainty**

There have been no significant judgements made in the process of preparing the financial statements.

There have been no key assumptions concerning the future and other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

**2 Donations and legacies**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Donations and sponsorship	<u><b>66,088</b></u>	<u>77,966</u>
	<u><b>66,088</b></u>	<u>77,966</u>

Income from donations, sponsorship and grants was £66,088 (2020: £77,966), £66,088 of which was unrestricted (2020: £77,156) and £Nil restricted (2020: £810).

**3 Charitable activities**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Membership and literary fees	<b>15,925</b>	15,245
Conference and events	<u><b>2,855</b></u>	<u>9,990</u>
	<u><b>18,780</b></u>	<u>25,235</u>

Income from charitable activities was £18,780 (2020: £25,235), all of which £18,780 (2020: £25,235) was unrestricted and £nil was restricted (2020: £nil).

**4 Other trading activities**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Fundraising events	-	6,572
Advertising	<u><b>5,100</b></u>	<u>6,800</u>
	<u><b>5,100</b></u>	<u>13,372</u>

Income from other trading activities was £5,100 (2020: £13,372), all of which was unrestricted.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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**5 Investment income**

	<b>2021</b>	<b>2020</b>
	£	£
Bank interest	92	-
General interest received	-	1,064
	<u>92</u>	<u>1,064</u>

Investment income was £92 (2020: £1,064) of which £92 (2020: £1,064) was unrestricted and £nil (2020: £nil) was restricted.

**6 Charitable activities**

	<b>2021</b>	<b>2020</b>
	£	£
<b><i>Direct costs</i></b>		
Publications	16,834	7,546
Research	2,880	829
Dietitian's fees and expenses	25,343	23,181
Conference and event costs	5,211	24,473
Grants awarded (see note below)	-	-
Sponsorship	444	-
Advocacy	-	-
<b><i>Support costs</i></b>		
Insurance	2,081	1,940
Administration fees and expenses	17,785	20,069
Meeting and conference expenses	377	2,092
Membership fees and subscriptions	1,453	1,449
Telephone	200	578
Bank and other charges	567	645
Travel	221	943
Post, stationery and advertising	3,312	3,026
Depreciation charge	1,499	1,119
Examination fees	1,602	2,700
	<u>79,810</u>	<u>90,590</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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**6 Charitable activities (continued)**

	<b>2021</b>	<b>2020</b>
	£	£
<b>Grants to individuals</b>		
Research grant for a home monitoring device	-	-
A grant for fruit and vegetables	-	-
A grant for travel to conference	-	-
	<u>-</u>	<u>-</u>
	<u>-</u>	<u>-</u>

There were no employees during the current and previous year.

Expenditure on charitable activities was £79,810 (2020: £90,590) of which £79,810 (2020: £90,590) was unrestricted and £nil (2020: £nil) was restricted.

Expenditure on raising funds in the current and previous year was unrestricted.

**7 Net income/(outgoings) resources**

	<b>2021</b>	<b>2020</b>
	£	£
Net incoming/(outgoing) resources are stated after charging/(crediting):		
Independent examiner's fees – current year (excluding VAT)	<b>1,425</b>	1,335
	<u>1,425</u>	<u>1,335</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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8 **Intangible assets**

<b>Cost/Valuation</b>	<b>2021</b> £	<b>2020</b> £
Balance b/fwd	7,494	2,450
Additions	-	5,044
Disposals	-	-
	<hr/>	<hr/>
Balance c/fwd	<b>7,494</b>	7,494
	<hr/> <hr/>	<hr/> <hr/>
<b>Depreciation</b>		
Balance b/fwd	999	-
Charge	1,499	999
Disposals	-	-
	<hr/>	<hr/>
Balance c/fwd	2,498	999
	<hr/> <hr/>	<hr/> <hr/>
<b>NBV</b>		
Balance c/fwd	<b>4,996</b>	6,495
	<hr/>	<hr/>
Balance b/fwd	<b>6,495</b>	2,450
	<hr/> <hr/>	<hr/> <hr/>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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9 **Fixed assets**

	<b>Computer equipment £</b>	<b>Total £</b>
<b>Cost</b>		
At 1 November 2020	430	430
Additions	-	-
Disposals	-	-
<b>At 31 October 2021</b>	<b>430</b>	<b>430</b>
<b>Depreciation</b>		
At 1 November 2020	430	430
Charge for the year	-	-
On disposals	-	-
<b>At 31 October 2021</b>	<b>430</b>	<b>430</b>
<b>Net book value</b>		
<b>At 31 October 2021</b>	-	-
At 31 October 2020	-	-

10 **Trustees' remuneration and expenses**

£nil has been paid to the trustees during the year ended 31 October 2021 to cover travel expenses and overnight stays and subsistence during conferences (2019: £1,699 to 5 trustees).

The trustees neither received nor waived any emoluments during the year (2020: £nil).

There are no other related party transactions.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

11 **Debtors: amounts falling due within one year**

	2021 £	2020 £
Prepayments and accrued income	-	1,083
Trade debtors	<u>4,539</u>	<u>1,625</u>
	<u>4,539</u>	2,708

12 **Creditors: amount falling due within one year**

	2021 £	2020 £
Trade creditors	1,719	3,020
Accruals	<u>1,428</u>	<u>1,428</u>
	3,147	4,448

13 **Funds**

Current year	Brought forward at 01/11/20 £	Incoming resources £	Outgoing resources £	Transfers £	Carried forward at 31/10/21 £
<b>Restricted funds:</b>					
Research funds	16,211	-	-	-	16,211
Website	4,654	-	-	-	4,654
Conference	-	-	-	-	-
	<u>20,865</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>20,865</u>
<b>Total restricted</b>	20,865	-	-	-	20,865
<b>Unrestricted funds:</b>					
<i>General reserve</i>	271,930	90,060	(79,810)	-	282,180
<i>Designated funds:</i>					
NSPKU Grant and research fund	20,000	-	-	-	20,000
	<u>291,930</u>	<u>90,060</u>	<u>(79,810)</u>	<u>-</u>	<u>302,180</u>
<b>Total unrestricted</b>	291,930	90,060	(79,810)	-	302,180
<b>Total funds</b>	<u>312,795</u>	<u>90,060</u>	<u>(79,180)</u>	<u>-</u>	<u>323,045</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

13 **Funds**

Prior year	Brought forward at 01/11/19 £	Incoming resources £	Outgoing resources £	Transfers £	Carried forward at 31/10/20 £
<b>Restricted funds:</b>					
Research funds	15,401	810	-	-	<b>16,211</b>
Website	9,698	-	-	(5,044)	<b>4,654</b>
Conference	-	-	-	-	-
<b>Total restricted</b>	<b>25,099</b>	<b>810</b>	<b>-</b>	<b>(5,044)</b>	<b>20,865</b>
<b>Unrestricted funds:</b>					
<i>General reserve</i>	243,665	116,827	(93,606)	5,044	<b>271,930</b>
<i>Designated funds:</i>					
NSPKU Grant and research fund	20,000	-	-	-	<b>20,000</b>
<b>Total unrestricted</b>	<b>263,665</b>	<b>116,827</b>	<b>(93,606)</b>	<b>5,044</b>	<b>291,930</b>
<b>Total funds</b>	<b>288,764</b>	<b>117,637</b>	<b>(93,606)</b>	<b>-</b>	<b>312,795</b>

**Restricted IT/ website fund**

Restricted funds were received for the development of IT systems and the website. They will be spent next year.

**Restricted conference fund**

Restricted funds spent on the annual conference

**Grant and research fund**

A comprehensive fund document has now been completed and is available for our members to apply to. The document is available on our website for downloading and can also be requested by our members via any of the Trustees or Support Staff. The fund will incorporate the Restricted Research Fund and the Assisted Places Scheme and covers a much wider basis for applications for funding.

**General reserve**

The General reserve represents the free funds of the charity which are not designated for particular purposes.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2021**

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14 **Analysis of net assets between funds (prior years)**

	<b>Unrestricted funds</b>	<b>Designated funds</b>	<b>Restricted funds</b>	<b>Total</b>
	<b>2020 £</b>	<b>2020 £</b>	<b>2020 £</b>	<b>2020 £</b>
Fixed assets	6,495	-	-	6,495
Cash	287,175	-	20,865	308,040
Other current assets / liabilities	(1,740)	-	-	(1,740)
	<hr/>	<hr/>	<hr/>	<hr/>
<b>Total</b>	291,930	-	20,865	312,795
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

## The National Society for Phenylketonuria (UK) Limited

MHA Moore and Smalley  
Richard House  
9 Winckley Square  
Preston  
PR1 3HP

Dear Sirs

### Financial statements for the year ended 31 October 2021

The following representations are made on the basis of enquiries of management and staff with relevant knowledge and experience such as we consider necessary in connection with your independent examination of the charitable company's financial statements for the year ended 31 October 2021. These enquiries have included inspection of supporting documentation where appropriate. All representations are made to the best of our knowledge and belief.

- 1 We acknowledge that the work performed by you is substantially less in scope than an audit performed in accordance with International Standards on Auditing (UK and Ireland) and that you do not express an audit opinion.
- 2 We confirm that the charitable company was entitled to exemption under section 144 of the Charities Act 2011 the requirement to have its financial statements for the financial year ended 31 October 2020 audited.
- 3 We have fulfilled our responsibilities as trustees as set out in the terms of your engagement letter dated 29 January 2020, under the Charities Act 2011 for preparing financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), for being satisfied that they give a true and fair view and for making accurate representations to you.
- 4 All the transactions undertaken by the charitable company have been properly reflected and recorded in the accounting records.
- 5 All the accounting records have been made available to you for the purpose of your independent examination. We have provided you with unrestricted access to all appropriate persons within the charitable company, and with all other records and related information requested, including minutes of all management and trustee meetings and correspondence with The Charity Commission.
- 6 The financial statements are free of material misstatements, including omissions.
- 7 We believe that the effect of uncorrected misstatements as set out in this letter is immaterial both individually and in total.
- 8 The charitable company has satisfactory title to all assets and there are no liens or encumbrances on the charitable company's assets, except for those that are disclosed in the notes to the financial statements.
- 9 All actual liabilities, contingent liabilities and guarantees given to third parties have been recorded or disclosed as appropriate.
- 10 We have no plans or intentions that may materially alter the carrying value and where relevant the fair value measurements or classification of assets and liabilities reflected in the financial statements.
- 11 Significant assumptions used by us in making accounting estimates, including those measured at fair value, are reasonable.

- 12 We have disclosed to you all claims in connection with litigation that have been, or are expected to be, received and such matters, as appropriate, have been properly accounted for, and disclosed in, the financial statements.
- 13 We have disclosed to you all known instances of non-compliance or suspected non-compliance with laws and regulations whose effects should be considered when preparing the financial statements.
- 14 Related party relationships and transactions have been appropriately accounted for and disclosed in the financial statements. We have disclosed to you all relevant information concerning such relationships and transactions and are not aware of any other matters which require disclosure in order to comply with legislative and accounting standards requirements.
- 15 All events subsequent to the date of the financial statements which require adjustment or disclosure have been properly accounted for and disclosed.
- 16 We believe that the charitable company's financial statements should be prepared on a going concern basis on the grounds that current and future sources of funding or support will be more than adequate for the charitable company's needs. We have considered a period of twelve months from the date of approval of the financial statements. We believe that no further disclosures relating to the charitable company's ability to continue as a going concern need to be made in the financial statements.
- 17 All grants, donations and other income, the receipt of which is subject to specific terms or conditions, have been notified to you. There have been no breaches of terms or conditions in the application of such income. No restricted income was received in the year ended 31 October 2020.
- 18 We approve the year end journals.
- 19 At the year end £36,096.42 was held in the COIF Investment Management Account.

Yours faithfully

*Eric Lange*

.....  
**E W Lange - Trustee**



.....  
**I Williamson - Trustee**

On behalf of the board of trustees

Date 27/07/2022.....

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**

England & Wales - Charity number 273670

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# Accounts

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Company No. 01256124

Charity No. 273670

**The National Society  
for Phenylketonuria  
(United Kingdom)  
Limited**

**(A registered charity and company  
limited by guarantee)**

**Report and Financial Statements**

**For The Year Ended  
31 October 2020**

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

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# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## CHARITY INFORMATION

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<b>Trustees/Directors/Council of Management:</b>	E W Lange A Thompson I E Williamson D Noble-Nesbit J Cardy L Lee	Chair Treasurer (appointed 29/02/20) Honorary Secretary
<b>Company Secretary:</b>	I E Williamson	
<b>Registered office:</b>	Richard House Winckley Square Preston PR1 3HP	
<b>Contact address:</b>	NSPKU PO Box 3143 Purley CR8 9DD	
<b>Company Number:</b>	01256124	
<b>Charity Number:</b>	273670	
<b>Independent examiner:</b>	Mrs N Mason FCA, DChA MHA Moore and Smalley Richard House Winckley Square Preston PR1 3HP	
<b>Bankers:</b>	HSBC 49a Fishergate Preston PR1 8BQ	
	CCLA Investment Management Ltd COIF Charity Funds 80 Cheapside London EC2V 6DZ	
	The Affirmative Deposit Fund for Charities Central Finance Board 9 Bonhill Street London EC2A 4 PE	
	Leeds Building Society 105 Albion Street Leeds LS1 5AS	
<b>Website:</b>	<a href="http://www.nspku.org">www.nspku.org</a>	
<b>Email:</b>	<a href="mailto:info@nspku.org">info@nspku.org</a>	

# **THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**

## **TRUSTEES' REPORT**

### **FOR THE YEAR ENDED 31 OCTOBER 2020**

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The trustees of The National Society for Phenylketonuria (United Kingdom) Limited who are also the directors for the purposes of the Companies Act, present their annual report and the financial statements for the year ended 31 October 2020, which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" (FRS 102) in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and 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 published October 2019.

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

##### **Governing document**

NSPKU is a charitable company limited by guarantee incorporated on 27 April 1976 and registered with the Charity Commission on 16 June 1977.

The charity is controlled by its governing document, Memorandum and Articles of Association dated 27 April 1976, as amended by Special Resolution dated 2 March 1991 and Special Resolution dated 19 March 2011.

##### **Recruitment, appointment, induction and training of new trustees**

Vacancies that arise from time to time as determined and agreed by the Council of Management shall be advertised in the Society Magazine and website in the first instance. Applicants will be vetted and appointed by the Senior Officers and appointees will be made aware of their legal obligations. Training will be given in line with Charity Commission procedures and the Charities SORP (Statement of Operating Recommended Practice). This is a position not to be taken lightly and an honest commitment is required. The same will apply to professionals supporting the society.

##### **Organisational structure**

The society is controlled by the Council of Management. Trustees during the year are shown on page 1. The Council meets at least four times a year and the senior officers meet separately up to twice a year.

The senior officers meet to discuss issues at greater length than is possible at Council of Management meetings. This allows them to define NSPKU policy proposals for discussion of the Council of Management.

All meetings mentioned above have minutes taken. Decisions will be made where possible by consensus; otherwise a majority vote will be used.

##### **Risk management**

The trustees have a duty to identify the risks to which the charity is exposed and have reviewed the risks and established appropriate systems or procedures to mitigate those risks.

#### **OBJECTIVES AND ACTIVITIES:**

##### **Objectives and activities for the public benefit**

The objectives of the charity are to promote the educational, medical and social welfare of persons suffering from phenylketonuria and similar disorders controlled by diet, to establish or encourage research in phenylketonuria and related disorders, to establish and maintain a fund or funds from which to make grants for

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## TRUSTEES' REPORT

FOR THE YEAR ENDED 31 OCTOBER 2020

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### Objectives and activities for the public benefit (continued)

the purpose of fulfilling the objects of the society, to invite, procure, appeal for, collect and receive and accept subscriptions, donations, legacies and gifts of money, investments or other property. The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives, and in planning future objectives.

### Grant making policy

The allocation of grants is decided on an individual basis as an application is made. The application where possible will be discussed by the Council of Management (anonymously if necessary) but if this is not possible a decision will be made by the senior officers and minutes taken at the next Committee of Management meeting. Where applicable, we shall seek guidance from our Medical Advisory Panel.

### Volunteers

All members of the Council of Management are volunteers. They are encouraged to contribute freely to all discussions and decisions made by the Council. Meetings have minutes taken to reflect discussions, decisions and dissensions.

### ACHIEVEMENT AND PERFORMANCE:

The financial year ending 31<sup>st</sup> October 2020 was overshadowed by Covid 19. Fortunately, we held our main event -our Annual Conference - earlier in the year in February 2020.

Given many charity events had been cancelled for example the London Marathon, the Council of Management were concerned about income generation (from our members and supporters) and also costs budgeted for the year. Consequently, we agreed an emergency budget in early April. It was shown that if things continued as was, the Charity would be facing a large five figure loss for the year.

As a result of the emergency budget, we suspended hard copy publications. All publications were published on the website, while News & Views was sent electronically to our members. Some working hours were restricted and as a result costs were cut. The fact that Edale and Keswick were also cancelled, contributed to cost savings as well. The Council of Management held virtual monthly meetings right through to the end of the financial year to monitor income and spent. These online meetings helped contribute to a reduction of our corporate governance costs for the year as well.

We recognise the tremendous effort made by our members and supporters (including industry) in helping to achieve this and maintain the integrity of our assets on behalf of our members. It was a tremendous team effort, and I can only thank them publicly for all their hard work in turning around the finances to deliver a surplus.

We can approach the 2020 financial year on a going concern basis with some confidence.

By not having any face-to-face events post Conference, we were conscious we needed to communicate virtually to our members to help through the Covid crisis and keep their spirits up. Naturally, this mitigated any risk of spreading the virus.

Our Conference was held in Maidstone, Kent this year and was well attended. On the Saturday news broke in the Daily Express that they would get behind our campaign to get sapropterin routinely commissioned. Several copies were purchased, and a short video made of the Conference attendees thanking them. They continue to support our campaign.

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## TRUSTEES' REPORT

### FOR THE YEAR ENDED 31 OCTOBER 2020

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On 28<sup>th</sup> June 2019 - International PKU Day – we held our first virtual event. This was essentially, a mini telethon that resulted not only a boost to our finances but also an increase in membership. Great appreciation goes to those who contributed their own time freely for this event.

Our Medical Advisory Panel met twice during the year and our Society dietitian started Friday meetings for dedicated dietitians to participate. Through this latter initiative, many publications have been updated and new ones written for members and the PKU Community. There is a currently an active production line of important publications – many of which have been posted already on our website.

Our Advocacy team has had several meetings with the All-Party Parliamentary Group and much progress has been made in obtaining important information for the Society to act on behalf of members. Despite the application for **Sapropterin** being rejected again by NHS England, The National Institute for Clinical Excellence (NICE) is conducting an appraisal which is expected in April 2021. NHS England called on the manufacturer to offer the drug at a fair price. If the NICE appraisal recommends Sapropterin for routine commissioning, the drug will be made available within England and Wales. NICE guidance is also usually followed in Northern Ireland. NHS England has also stated that it would also commission any generic version(s) of Sapropterin from the next financial year onwards (2021) on the condition that these manufacturers price their products below the maximum level NICE advises as representing a clinically and cost-effective use of NHS resources.

In addition to the above, our support staff – together with the Advocacy team have acted on behalf of many members in obtaining Disability Living Allowance (SLA) and Personal Independence Payments (PIP).

#### **The Year Ahead**

Any Conference we have in 2021 is expected to be a day Conference in the North West of England.

At this stage, both Edale and Keswick will go ahead as usual.

We shall look to build on International PKU Day video telethon our video conference. Coupled with this, it is likely our “Spring Draw” will become our “Summer Draw” and we shall potentially hold this at the same time.

We shall look to NICE for a positive report on Sapropterin in April and advocate for routine commissioning. We do have input into this appraisal and we hope we can influence the decision for a positive response so that PKU Patients can benefit throughout the UK.

Our News and Views will be produced in hard copy in 2021 as we do not anticipate a severe financial downside and many members were thrilled to get their hard copy “back” in late November 2020.

No grants for research were made in the financial year due to financial pressures and many researchers either being furloughed, or research stopped. However, we shall pay for food analysis of some foods in the year. Analysis of phenylalanine content in natural foods is not cheap so we need to be selective in what we pay for.

Of vital importance is the PKU network within the UK. We aim to foster support groups throughout the country. If you wish to start one, please get in touch at [info@nspku.org](mailto:info@nspku.org).

We extend our gratitude to all our support staff for all their hard work for the year including the transition of the position of Administrator from Caroline Bridges to Alison Green. Caroline has been a tremendous help to the Society during her tenure as Administrator and helped with a smooth handover earlier in the year. We wish her and her family the very best for the future.

To all our members and the wider PKU Community a sincere thank you to all for your contributions to the NSPKU – be they financial or otherwise.

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## TRUSTEES' REPORT

FOR THE YEAR ENDED 31 OCTOBER 2020

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### FINANCIAL REVIEW:

The net incoming resources for the year were £24,031 (2019: (£25,489)), details of which are shown on the Statement of Financial Activities.

### Reserves policy

At 31 October 2020 £15,401 (2019: £15,401) was held in the restricted research fund, £4,654 was held in a restricted fund for the new website (2019: £9,698), £272,740 (2019: £243,665) was held in the general unrestricted fund and £20,000 (2019: £20,000) was held in a designated grant and research fund. £266,245 (2019: £241,095) are free reserves.

The society regularly reviews the reserves of the charity by means of the treasurer's report at each meeting, which details all monies held by the charity, including investments and restricted funds. The trustees' policy is to hold reserves to cover a minimum of two year's fixed expenditure which is currently around £180,000 year. Free reserves are to be used to fund new activities in the future.

Sources of funding are shown in the Statement of Financial Activities and in the notes to the accounts.

### Investment policy and objectives

The society's policy is to hold surplus funds in building society and deposit accounts.

### Small company provisions

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

This report was approved by the trustees on ...28/07/2021.....and signed on their behalf by:

*Eric Lange*

.....

**E W Lange – Chair**

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES**  
**FOR THE YEAR ENDED 31 OCTOBER 2020**

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I report to the charity trustees on my examination of the accounts of the company for the year ended 31 October 2020 which are set out on pages 7 to 18.

**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**

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 in any material respect:

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;
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 the report in order to enable a proper understanding of the account to be reached.

*Nicola Mason*

**N Mason FCA, DChA**  
**MHA Moore and Smalley**  
**Chartered Accountants**  
**Preston**

Date 28/07/2021.....

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**STATEMENT OF FINANCIAL ACTIVITIES (INC INCOME AND EXPENDITURE ACCOUNT)**  
**FOR THE YEAR ENDED 31 OCTOBER 2020**

<b>Income</b>	<b>Note</b>	<b>Unrestricted funds £</b>	<b>Restricted funds £</b>	<b>Total funds 2020 £</b>	<b>Total funds 2019 £</b>
Donations, grants and legacies	2	77,156	810	77,966	64,469
Income from charitable activities	3	25,235	-	25,235	53,169
Income from other trading activities	4	13,372	-	13,372	12,207
Investment income	5	1,064	-	1,064	1,357
<b>Total income</b>		<b>116,827</b>	<b>810</b>	<b>117,637</b>	<b>131,202</b>
<b>Resources expended</b>					
<i>Costs of raising funds:</i>					
Fundraising trading: cost of goods sold and other costs		3,016	-	3,016	1,387
Charitable activities	6	90,590	-	90,590	104,326
<b>Total expenditure</b>		<b>93,606</b>	<b>-</b>	<b>93,606</b>	<b>105,713</b>
<b>Net income/(expenditure) for the year</b>		<b>23,221</b>	<b>810</b>	<b>24,031</b>	<b>25,489</b>
Transfers between funds		5,044	(5,044)	-	-
<b>Net movement in funds</b>		<b>28,265</b>	<b>(4,234)</b>	<b>24,031</b>	<b>25,489</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		263,665	25,099	288,764	263,275
<b>Total funds carried forward</b>		<b>291,930</b>	<b>20,865</b>	<b>312,795</b>	<b>288,764</b>

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing activities. The notes on pages 9 to 18 form part of these accounts.

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## BALANCE SHEET

AS AT 31 OCTOBER 2020

	Note	Unrestricted funds £	Restricted funds £	Total funds 2020 £	Total funds 2019 £
<b>Fixed assets</b>					
Intangible assets	8	6,495	-	6,495	2,450
Tangible assets	9	-	-	-	120
		<b>6,495</b>	<b>-</b>	<b>6,495</b>	<b>2,570</b>
<b>Current assets</b>					
Debtors	11	2,708	-	2,708	31,328
Cash at bank and in hand		287,175	20,865	308,040	289,656
		<b>289,883</b>	<b>20,865</b>	<b>310,748</b>	<b>320,984</b>
<b>Creditors: Amounts falling due within one year</b>	12	<b>(4,448)</b>	<b>-</b>	<b>(4,448)</b>	<b>(34,790)</b>
<b>Net current assets</b>		<b>285,435</b>	<b>20,865</b>	<b>306,300</b>	<b>286,194</b>
<b>Net assets</b>		<b>291,930</b>	<b>20,865</b>	<b>312,795</b>	<b>288,764</b>
<b>Funds</b>	13				
Unrestricted – general		271,930	810	272,740	243,665
Unrestricted -designated		20,000	-	20,000	20,000
Restricted		-	20,055	20,055	25,099
<b>Total funds</b>		<b>291,930</b>	<b>20,865</b>	<b>312,795</b>	<b>288,764</b>

For the year ending 31 October 2020 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

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

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

These financial statements were approved by the trustees and authorised for issue on 28/07/2021 and are signed on their behalf by:

*Eric Lange*

.....  
E W Lange - Chair  
Company number: 01256124



.....  
I Williamson – Secretary

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31 OCTOBER 2020

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### 1 Accounting policies

#### Basis of preparation

The National Society for Phenylketonuria (United Kingdom) Limited is an incorporated charity registered in England. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are explained in the Trustees Report.

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with 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) issued on October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention. The financial statements are prepared in sterling which is the functional currency of the and rounded to the nearest £.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years.

#### Going concern

The trustees assess whether the use of going concern is appropriate i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt on the ability of the company to continue as a going concern. The trustees make this assessment in respect of a period of at least one year from the date of authorisation for issue of the financial statements and have concluded that the charity has adequate resources to continue in operational existence for the foreseeable future and there are no material uncertainties about the charity's ability to continue as a going concern, thus they continue to adopt the going concern basis of accounting in preparing the financial statements.

#### Incoming resources

All incoming resources are included on the Statement of Financial Activities when the charity is legally entitled to the income, the amount can be quantified with reasonable accuracy and it is probable that the income will be received.

Grants are recognised in the SOFA when receivable. When donors specify that grants given to the charity must be used in the future financial years, the income is deferred until that year. Assets and investments donated to the charity are included as donation income at market value at the time of the receipt.

No amount is included in the financial statements for volunteer time in line with the SORP (FRS 102).

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2020**

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**1 Accounting policies (continued)**

**Resources expended**

The charity is not registered for VAT. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs 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.

Charitable expenditure comprises those costs incurred by the charity on delivery of its activities and services, including those costs of any indirect nature necessary to support them.

**Taxation**

As a registered charity, the society is exempt from corporation tax on its charitable activities to the extent that these are applied to its charitable objects.

**Intangible assets**

Intangible assets are amortised on a straight-line basis over their useful lives. The useful lives of intangible assets are as follows:

Website - 5 years straight line

Provision is made for any impairment.

**Fixed assets**

Tangible fixed assets are stated at cost less accumulated depreciation. Cost includes costs directly attributable to making the asset capable of operating as intended.

Depreciation is provided on all tangible fixed assets, at rates calculated to write off the cost, less estimated residual value, of each asset on a systematic basis over its expected useful life as follows:

Computer equipment - 33% on cost

**Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Designated funds comprise unrestricted funds that have been set aside by the trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the financial statements.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2020**

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**1 Accounting policies (continued)**

**Judgements and key sources of estimation uncertainty**

There have been no significant judgements made in the process of preparing the financial statements.

There have been no key assumptions concerning the future and other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

**2 Donations and legacies**

	<b>2020</b> £	<b>2019</b> £
Donations and sponsorship	<u>77,966</u>	<u>64,469</u>
	<b>77,966</b>	<b>64,469</b>

Income from donations, sponsorship and grants was £77,966 (2019: £64,469), £77,156 of which was unrestricted (2019: £64,469) and £810 restricted (2019: nil).

**3 Charitable activities**

	<b>2020</b> £	<b>2019</b> £
Restricted grants	-	20,000
Membership and literary fees	<b>15,245</b>	13,909
Conference and events	<u>9,990</u>	<u>19,260</u>
	<b>25,235</b>	<b>53,169</b>

Income from charitable activities was £25,235 (2019: £53,169), all of which £25,235 (2019: £33,169) was unrestricted and £nil was restricted (2019: £20,000).

**4 Other trading activities**

	<b>2020</b> £	<b>2019</b> £
Fundraising events	<b>6,572</b>	5,407
Advertising	<u>6,800</u>	<u>6,800</u>
	<b>13,372</b>	<b>12,207</b>

Income from other trading activities was £13,372 (2019: £12,207), all of which was unrestricted.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**

**NOTES TO THE ACCOUNTS**

**FOR THE YEAR ENDED 31 OCTOBER 2020**

**5 Investment income**

	<b>2020</b>	<b>2019</b>
	£	£
Bank interest	-	106
General interest received	<u>1,064</u>	<u>1,251</u>
	<b>1,064</b>	<b>1,357</b>

Investment income was £1,064 (2019: £1,357) of which £1,064 (2019: £1,357) was unrestricted and £nil (2019: £nil restricted).

**6 Charitable activities**

	<b>2020</b>	<b>2019</b>
	£	£
<b><i>Direct costs</i></b>		
Publications	<b>7,546</b>	16,744
Research	<b>829</b>	-
Dietitian's fees and expenses	<b>23,181</b>	23,357
Conference and event costs	<b>24,473</b>	32,768
Grants awarded (see note below)	-	(9,593)
Sponsorship	-	1,000
Advocacy	-	3,399
<b><i>Support costs</i></b>		
Insurance	<b>1,940</b>	1,886
Administration fees and expenses	<b>20,069</b>	22,197
Meeting and conference expenses	<b>2,092</b>	4,373
Membership fees and subscriptions	<b>1,449</b>	1,410
Telephone	<b>578</b>	812
Bank and other charges	<b>645</b>	562
Travel	<b>943</b>	1,530
Post, stationery and advertising	<b>3,026</b>	2,103
Depreciation charge	<b>1,119</b>	143
Examination fees	<b>2,700</b>	1,635
	<u><b>90,590</b></u>	<u>104,326</u>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
**FOR THE YEAR ENDED 31 OCTOBER 2020**

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**6 Charitable activities (continued)**

	<b>2020</b>	<b>2019</b>
	<b>£</b>	<b>£</b>
<b><i>Grants to individuals</i></b>		
Research grant for a home monitoring device	-	(10,000)
A grant for fruit and vegetables	-	340
A grant for travel to conference	-	67
	<u>-</u>	<u>(9,593)</u>

There were no employees during the current and previous year.

Expenditure on charitable activities was £90,590 (2019: £104,326) of which £90,590 (2019: £103,617) was unrestricted and £nil (2019: £709) was restricted.

Expenditure on raising funds in the current and previous year was unrestricted.

**7 Net income/(outgoings) resources**

	<b>2020</b>	<b>2019</b>
	<b>£</b>	<b>£</b>
Net incoming/(outgoing) resources are stated after charging/(crediting):		
Independent examiner's fees – current year (excluding VAT)	<b>1,335</b>	1,362
	<u>1,335</u>	<u>1,362</u>

# THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED

## NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31 OCTOBER 2020

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### 8 Intangible assets

A website costing £2,450 has additions of £5,044 in the current year and will be depreciated once it is completed.

<b>Cost/Valuation</b>	<b>2020</b> <b>£</b>	<b>2019</b> <b>£</b>
Balance b/fwd	<b>2,450</b>	2,450
Additions	<b>5,044</b>	-
Disposals	-	-
	<hr/>	<hr/>
Balance c/fwd	<b>7,494</b>	2,450
	<hr/>	<hr/>
<b>Depreciation</b>		
Balance b/fwd	-	-
Charge	999	-
Disposals	-	-
	<hr/>	<hr/>
Balance c/fwd	999	-
	<hr/>	<hr/>
NBV		
Balance c/fwd	<b>6,495</b>	2,450
	<hr/>	<hr/>
Balance b/fwd	<b>2,450</b>	2,450
	<hr/>	<hr/>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
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9 **Fixed assets**

	<b>Computer equipment £</b>	<b>Total £</b>
<b>Cost</b>		
At 1 November 2019	430	430
Additions	-	-
Disposals	-	-
<b>At 31 October 2020</b>	<b>430</b>	<b>430</b>
	=====	=====
<b>Depreciation</b>		
At 1 November 2019	310	310
Charge for the year	120	120
On disposals	-	-
<b>At 31 October 2020</b>	<b>430</b>	<b>430</b>
	=====	=====
<b>Net book value</b>		
<b>At 31 October 2020</b>	<b>-</b>	<b>-</b>
	=====	=====
At 31 October 2019	120	120
	=====	=====

10 **Trustees' remuneration and expenses**

£1,699 has been paid to the trustees during the year ended 31 October 2020 to cover travel expenses and overnight stays and subsistence during conferences (2019: £4,195 to 5 trustees). £15 has also been paid the Trustees to cover telephone costs.

The trustees neither received nor waived any emoluments during the year (2019: £nil).

There are no other related party transactions.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
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11 **Debtors: amounts falling due within one year**

	<b>2020</b>	<b>2019</b>
	£	£
Prepayments and accrued income	<b>1,083</b>	15,300
Trade debtors	<b>1,625</b>	16,028
	<b>2,708</b>	31,328

12 **Creditors: amount falling due within one year**

	<b>2020</b>	<b>2019</b>
	£	£
Trade creditors	<b>3,020</b>	33,362
Accruals	<b>1,428</b>	1,428
	<b>4,448</b>	34,790

13 **Funds**

<b>Current year</b>	<b>Brought forward at 01/11/19</b>	<b>Incoming resources</b>	<b>Outgoing resources</b>	<b>Transfers</b>	<b>Carried forward at 31/10/20</b>
	£	£	£	£	£
<b>Restricted funds:</b>					
Research funds	15,401	810	-	-	<b>16,211</b>
Website	9,698	-	-	(5,044)	<b>4,654</b>
Conference	-	-	-	-	-
<b>Total restricted</b>	<b>25,099</b>	<b>810</b>	<b>-</b>	<b>(5,044)</b>	<b>20,865</b>
<b>Unrestricted funds:</b>					
<i>General reserve</i>	243,665	116,827	(93,606)	5,044	<b>271,930</b>
<i>Designated funds:</i>					
NSPKU Grant and research fund	20,000	-	-	-	<b>20,000</b>
<b>Total unrestricted</b>	<b>263,665</b>	<b>116,827</b>	<b>(93,606)</b>	<b>5,044</b>	<b>291,930</b>
<b>Total funds</b>	<b>288,764</b>	<b>117,637</b>	<b>(93,606)</b>	<b>-</b>	<b>312,795</b>

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
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13 **Funds**

Prior year	Brought forward at 01/11/18 £	Incoming resources £	Outgoing resources £	Transfers £	Carried forward at 31/10/19 £
<b>Restricted funds:</b>					
Research funds	15,808	-	(407)	-	15,401
Website	-	10,000	(302)	-	9,698
Conference	-	10,000	(10,000)	-	-
<b>Total restricted</b>	<b>15,808</b>	<b>20,000</b>	<b>(10,709)</b>	<b>-</b>	<b>25,099</b>
<b>Unrestricted funds:</b>					
<i>General reserve</i>	217,467	111,202	(105,004)	20,000	243,665
<i>Designated funds:</i>					
NSPKU Grant and research fund	30,000	-	10,000	(20,000)	20,000
<b>Total unrestricted</b>	<b>247,467</b>	<b>111,202</b>	<b>(95,004)</b>	<b>-</b>	<b>263,665</b>
<b>Total funds</b>	<b>263,275</b>	<b>131,202</b>	<b>(105,713)</b>	<b>-</b>	<b>288,764</b>

**Restricted IT/ website fund**

Restricted funds were received for the development of IT systems and the website. They will be spent next year.

**Restricted conference fund**

Restricted funds spent on the annual conference

**Grant and research fund**

A comprehensive fund document has now been completed and is available for our members to apply to. The document is available on our website for downloading and can also be requested by our members via any of the Trustees or Support Staff. The fund will incorporate the Restricted Research Fund and the Assisted Places Scheme and covers a much wider basis for applications for funding.

**General reserve**

The General reserve represents the free funds of the charity which are not designated for particular purposes.

**THE NATIONAL SOCIETY FOR PHENYLKETONURIA (UNITED KINGDOM) LIMITED**  
**NOTES TO THE ACCOUNTS**  
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14 **Analysis of net assets between funds (prior years)**

	Unrestricted funds	Designated funds	Restricted funds	Total
	2019 £	2019 £	2019 £	2019 £
<b>Fixed assets</b>	2,570	-	-	2,570
Cash	254,255	20,000	15,401	289,656
Other current assets / liabilities	(13,160)	-	9,698	(3,462)
	<hr/>	<hr/>	<hr/>	<hr/>
<b>Total</b>	243,665	20,000	25,099	288,764
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

## The National Society for Phenylketonuria (UK) Limited

MHA Moore and Smalley  
Richard House  
9 Winckley Square  
Preston  
PR1 3HP

Dear Sirs

### Financial statements for the year ended 31 October 2020

The following representations are made on the basis of enquiries of management and staff with relevant knowledge and experience such as we consider necessary in connection with your independent examination of the charitable company's financial statements for the year ended 31 October 2020. These enquiries have included inspection of supporting documentation where appropriate. All representations are made to the best of our knowledge and belief.

- 1 We acknowledge that the work performed by you is substantially less in scope than an audit performed in accordance with International Standards on Auditing (UK and Ireland) and that you do not express an audit opinion.
- 2 We confirm that the charitable company was entitled to exemption under section 144 of the Charities Act 2011 the requirement to have its financial statements for the financial year ended 31 October 2020 audited.
- 3 We have fulfilled our responsibilities as trustees as set out in the terms of your engagement letter dated 29 January 2020, under the Charities Act 2011 for preparing financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), for being satisfied that they give a true and fair view and for making accurate representations to you.
- 4 All the transactions undertaken by the charitable company have been properly reflected and recorded in the accounting records.
- 5 All the accounting records have been made available to you for the purpose of your independent examination. We have provided you with unrestricted access to all appropriate persons within the charitable company, and with all other records and related information requested, including minutes of all management and trustee meetings and correspondence with The Charity Commission.
- 6 The financial statements are free of material misstatements, including omissions.
- 7 We believe that the effect of uncorrected misstatements as set out in this letter is immaterial both individually and in total.
- 8 The charitable company has satisfactory title to all assets and there are no liens or encumbrances on the charitable company's assets, except for those that are disclosed in the notes to the financial statements.
- 9 All actual liabilities, contingent liabilities and guarantees given to third parties have been recorded or disclosed as appropriate.
- 10 We have no plans or intentions that may materially alter the carrying value and where relevant the fair value measurements or classification of assets and liabilities reflected in the financial statements.
- 11 Significant assumptions used by us in making accounting estimates, including those measured at fair value, are reasonable.

- 12 We have disclosed to you all claims in connection with litigation that have been, or are expected to be, received and such matters, as appropriate, have been properly accounted for, and disclosed in, the financial statements.
- 13 We have disclosed to you all known instances of non-compliance or suspected non-compliance with laws and regulations whose effects should be considered when preparing the financial statements.
- 14 Related party relationships and transactions have been appropriately accounted for and disclosed in the financial statements. We have disclosed to you all relevant information concerning such relationships and transactions and are not aware of any other matters which require disclosure in order to comply with legislative and accounting standards requirements.
- 15 All events subsequent to the date of the financial statements which require adjustment or disclosure have been properly accounted for and disclosed.
- 16 We believe that the charitable company's financial statements should be prepared on a going concern basis on the grounds that current and future sources of funding or support will be more than adequate for the charitable company's needs. We have considered a period of twelve months from the date of approval of the financial statements. We believe that no further disclosures relating to the charitable company's ability to continue as a going concern need to be made in the financial statements.
- 17 All grants, donations and other income, the receipt of which is subject to specific terms or conditions, have been notified to you. There have been no breaches of terms or conditions in the application of such income. No restricted income was received in the year ended 31 October 2020.
- 18 We approve the year end journals.
- 19 At the year end £36,096.42 was held in the COIF Investment Management Account.

Yours faithfully

*Eric Lange*

.....  
**E W Lange - Trustee**



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**I Williamson - Trustee**

On behalf of the board of trustees

Date 28/07/2021.....