

Company registration number: 07000073  
Charity registration number: 1133182

**ADVOCACY FOR NEUROACANTHOCYTOSIS PATIENTS  
TRUSTEES' REPORT AND  
FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 AUGUST 2025**

Orcadia  
1-3 East Road  
Kirkwall  
Orkney  
KW15 1HZ

**Advocacy For Neuroacanthocytosis Patients**  
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**Advocacy For Neuroacanthocytosis Patients**  
**Company No. 07000073**  
**Trustees' Report For The Year Ended 31 August 2025**

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The trustees present their report and the financial statements for the year ended 31 August 2025.

## **Objectives and Activities**

### **Public Benefit**

The Advocacy for Neuroacanthocytosis Patients benefits a group of patients around the world who suffer from two very rare chronic neurodegenerative conditions: VPS13A disease (Chorea-acanthocytosis) and XK disease (McLeod Syndrome) that often begin in early adulthood and leave patients wholly dependent on carers. We have newly diagnosed / potential patients or their families or carers from all over the world who contact us as a result of searching for information about VPS13A and XK diseases. The world-wide figure is only speculative, but it is likely to be approximately 3,000. The Advocacy works with patient groups for Huntington's disease and neurodegeneration with brain iron accumulation (NBIA) that includes PKAN, a related disease that affects children. We are the only charity in the UK supporting those with the adult neuroacanthocytosis (NA) diseases.

The specific public benefit objectives of the Advocacy are:

- To promote and protect the physical and mental health of sufferers of NA diseases and their families through the provision of support, education and practical advice.
- To advance the education of health professionals and the general public in all areas relating to NA syndromes.

The trustees confirm that they have complied with the requirements of Section 17 of the Charities Act 2011 to have due regard to the Charity Commission's guidance on public benefit.

## **Achievements and Performance**

### **Main Achievements**

#### **Charitable activities**

**Promoting and protecting the physical and mental health of sufferers of NA syndromes and their families through the provision of support, education and practical advice.**

1) In November 2024, February and July 2025 we published our e-newsletter that supports the growth of a community by sharing patient experiences and information that may be of practical help with the debilitating symptoms that affect patients, beginning in early adulthood and leaving patients wholly dependent on carers. Our direct contact with the families of newly diagnosed patients has encouraged people who otherwise feel completely isolated by this very rare disease.

2) Patients have added their stories to the multi-lingual website sharing experiences of things that have both helped patients' well-being and suggested ways for patients to support research to find a therapy. Through email, phone and personal meetings, we have frequent contact with the families of patients and we bring their voices and experiences to the medical community.

3) The Advocacy supports the new VPS13 Forums held online. Arising from the 10th Symposium in March of 2021 the international community of clinicians, scientists and families dealing with VPS13A disease and XK disease, respectively, the Advocacy continues the conversations by supporting and publicising the virtual meeting. Four new Forums have been held this year.

4) The Advocacy supports a free diagnostic service offered by Dr. Kevin Peikert at the Universitätsmedizin Rostock in Germany. The test is free. Since 2006 over 700 patients have had the diagnostic test in duplicate, which ensures the accuracy of the Western blot test (reduced false positives).

**Advancing the education of health professionals and the general public in all areas relating to neuroacanthocytosis.**

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**Advocacy For Neuroacanthocytosis Patients  
Trustees' Report (continued)  
For The Year Ended 31 August 2025**

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**Main Achievements - continued**

- 1) The 12th global NA Symposium was planned for September 2025 in Lausanne, Switzerland. Scientific and patient-oriented sessions will be held over three days.
- 2) The Advocacy continues to support the creation of an international patient registry in which consistent histories of anonymous, diagnosed patients can be studied and eventually be a source of candidates for drug trials. The existent NA Registry is hosted under the European Huntington Disease registry (EHDN). A separate registry of VPS13A mutations is hosted within the open-access Leiden Open Variation Database (LOVD).
- 3) The third Glenn Irvine Prize is to be presented at the 12th Symposium. The calendar of the process to find the winner is continually being coordinated by the Advocacy, consultants and researchers. This prize is both a reward for excellent work and intended to encourage further work in the study of NA syndromes.

**Financial Review**

**Financial Position**

The charity ended the year with reserves at 31 August 2025 of £41,133. The Euro account has been closed and had no outstanding balance. The charity designates funds specifically for any grants where research has already commenced.

**Reserves Policy**

The Advocacy's policy is to commit its full resources to its educational and research work each year. The charity has very limited expenses as the work is done by one full time paid staff and volunteers, all using home office facilities.

**Going Concern**

**Future Plans**

The charity plans to continue to focus on:

- 1) Communicating with patients and their families through personal contact by email, social media channels, phone, visits and through the website to increase the communication between patients' families. We will continue to bring news of developing therapies such as deep brain stimulation and to present the opportunity for patients to help with blood and tissue donations for expanding research. Patients' families can exchange messages of experiences and concern.
- 2) Providing support for communication and tissue acquisition to the related research at Rostock, Verona, Milan, Stony Brook, Mount Sinai and Michigan universities.
- 3) Promoting and supporting new scientific research. We accept grant requests on an ad-hoc basis and evaluate them through the Research Advisory Committee (RAC).
- 4) Making future provision in its research grant conditions to continue to encourage collaboration between researchers globally working in the lipidomics field and other relevant areas as they emerge.
- 5) Continuing to expand registry development in conjunction with newer opportunities in the field and to coordinate with the US Advocacy.
- 6) Launching the next call for the Glenn Irvine Prize to encourage young researchers and scientists to work in rare disease environments.

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**Advocacy For Neuroacanthocytosis Patients  
Trustees' Report (continued)  
For The Year Ended 31 August 2025**

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**Going Concern - continued**

7) Setting the Symposiums in locations to encourage interactions, exchange of ideas and networking opportunities among all participants. Young faculty and students use the opportunity to present their work during the poster sessions. The meetings also afford the scientists an opportunity to meet patients first-hand - in Lausanne, Switzerland in September 2025 and in Warsaw, Poland in 2027. Patients and family members will again hear the type of research work which is on-going and the Advocacy is supporting through research grants.

8) Continuing to communicate and share information with the US Advocacy to expand the efforts of fundraising, communicating with patients and providing support for research projects.

9) Searching for partnerships with umbrella groups and businesses willing to support the charity by continuing our relationship with Aspire Biosciences, Beacon and Eurordis.

**Structure, Governance and Management**

**Governing Document**

The charity is controlled by its governing document, Articles and Memorandum of Association, and constitutes a limited company, limited by guarantee as defined by the Companies Act 2006.

**Trustee Selection Methods**

New trustees are elected solely by the present trustees and all trustees will be subject to limited terms of office.

The trustees meet quarterly in a formal meeting with an agenda set out in advance. Trustees and officers are volunteers. There is one full time employee who commenced on 3 May 2023.

**Reference and Administrative Details**

**Trustees**

Mrs Nicola Keat  
Mrs Virginia Irvine  
Miss Mary Leigh-Wood  
Professor Adrian Danek  
Mr Neil Price (resigned 24/09/2025)  
Dr Peter Mills

**Company Secretary**

Mrs Virginia Irvine

**Charity Number**

1133182

**Company Number**

07000073

**Advocacy For Neuroacanthocytosis Patients  
Trustees' Report (continued)  
For The Year Ended 31 August 2025**

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**Independent Examiner**

Doris Hutchison CA, ATT  
Orcadia  
1-3 East Road  
Kirkwall  
Orkney  
KW15 1HZ

**Advocacy For Neuroacanthocytosis Patients  
Trustees' Report (continued)  
For The Year Ended 31 August 2025**

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The trustees' report was approved by the board of trustees and signed on its behalf by:

X *Virginia Irvine*

Mrs Virginia Irvine

Trustee

4 May 2026

**Advocacy For Neuroacanthocytosis Patients**  
**Independent Examiner's Report to the Trustees of Advocacy For Neuroacanthocytosis Patients**  
**For The Year Ended 31 August 2025**

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I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 August 2025.

**Responsibilities and Basis of Report**

As the charity 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.



Doris Hutchison CA, ATT

6 May 2026  
1-3 East Road  
Kirkwall  
Orkney  
KW15 1HZ



**Advocacy For Neuroacanthocytosis Patients**  
**Statement of Financial Activities (including Income and Expenditure Account)**  
**For The Year Ended 31 August 2025**

				2025	2024
		Unrestricted funds	Restricted funds	Total funds	Total funds
	Notes	£	£	£	£
<b>INCOME AND ENDOWMENTS FROM:</b>					
Donations and legacies	3	65,398	-	65,398	45,207
Investments	4	3,000	2,268	5,268	5,037
		<u>68,398</u>	<u>2,268</u>	<u>70,666</u>	<u>50,244</u>
<b>EXPENDITURE ON:</b>					
Charitable activities:	5				
Research Grants and Symposium		(8,147)	-	(8,147)	(9,000)
Other Resources Expended		(38,428)	(700)	(39,128)	(43,008)
		<u>(46,575)</u>	<u>(700)</u>	<u>(47,275)</u>	<u>(52,008)</u>
<b>NET INCOME/(EXPENDITURE) BEFORE INVESTMENT GAINS/(LOSSES)</b>		21,823	1,568	23,391	(1,764)
Net gains on investments		(1)	7,399	7,398	7,842
<b>NET INCOME/(EXPENDITURE)</b>		<u>21,822</u>	<u>8,967</u>	<u>30,789</u>	<u>6,078</u>
<b>NET MOVEMENT IN FUNDS</b>		21,822	8,967	30,789	6,078
<b>RECONCILIATION OF FUNDS:</b>					
Total funds brought forward		81,576	121,849	203,425	197,347
<b>TOTAL FUNDS CARRIED FORWARD</b>	13	<u>103,398</u>	<u>130,816</u>	<u>234,214</u>	<u>203,425</u>

The notes on pages 11 to 16 form part of these financial statements.

**Advocacy For Neuroacanthocytosis Patients**  
**Comparative Statement of Financial Activities (including Income and Expenditure Account)**  
**For The Year Ended 31 August 2025**

				2024
		Unrestricted funds	Restricted funds	Total funds
	Notes	£	£	£
<b>INCOME AND ENDOWMENTS FROM:</b>				
Donations and legacies	3	45,207	-	45,207
Investments	4	842	4,195	5,037
		<u>46,049</u>	<u>4,195</u>	<u>50,244</u>
<b>EXPENDITURE ON:</b>				
Charitable activities:	5			
Research Grants and Symposium		(9,000)	-	(9,000)
Other Resources Expended		(37,336)	(5,672)	(43,008)
		<u>(46,336)</u>	<u>(5,672)</u>	<u>(52,008)</u>
<b>NET EXPENDITURE BEFORE INVESTMENT LOSSES</b>		<u>(287)</u>	<u>(1,477)</u>	<u>(1,764)</u>
Net gains on investments		-	7,842	7,842
<b>NET EXPENDITURE</b>		<u>(287)</u>	<u>6,365</u>	<u>6,078</u>
<b>NET MOVEMENT IN FUNDS</b>		<u>(287)</u>	<u>6,365</u>	<u>6,078</u>
<b>RECONCILIATION OF FUNDS:</b>				
Total funds brought forward		81,863	115,484	197,347
<b>TOTAL FUNDS CARRIED FORWARD</b>	13	<u>81,576</u>	<u>121,849</u>	<u>203,425</u>

The notes on pages 11 to 16 form part of these financial statements.

**Advocacy For Neuroacanthocytosis Patients**  
**Balance Sheet**  
**As At 31 August 2025**

				<b>2025</b>	<b>2024</b>
		<b>Unrestricted</b>	<b>Restricted</b>	<b>Total</b>	<b>Total</b>
	<b>Notes</b>	<b>funds</b>	<b>funds</b>	<b>funds</b>	<b>funds</b>
		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
<b>CURRENT ASSETS</b>					
Debtors	<b>10</b>	266	-	266	227
Investments	<b>11</b>	70,841	124,446	195,287	186,321
Cash at bank and in hand		34,763	6,370	41,133	19,827
		<u>105,870</u>	<u>130,816</u>	<u>236,686</u>	<u>206,375</u>
<b>Creditors: Amounts Falling Due Within One Year</b>	<b>12</b>	<u>(2,472)</u>	<u>-</u>	<u>(2,472)</u>	<u>(2,950)</u>
<b>NET CURRENT ASSETS (LIABILITIES)</b>		<u>103,398</u>	<u>130,816</u>	<u>234,214</u>	<u>203,425</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>103,398</u>	<u>130,816</u>	<u>234,214</u>	<u>203,425</u>
<b>NET ASSETS</b>		<u>103,398</u>	<u>130,816</u>	<u>234,214</u>	<u>203,425</u>
<b>FUNDS OF THE CHARITY</b>					
Restricted Funds				130,816	121,849
Unrestricted Funds				103,398	81,576
<b>TOTAL FUNDS</b>	<b>13</b>			<u>234,214</u>	<u>203,425</u>

**Advocacy For Neuroacanthocytosis Patients**  
**Balance Sheet (continued)**  
**As At 31 August 2025**

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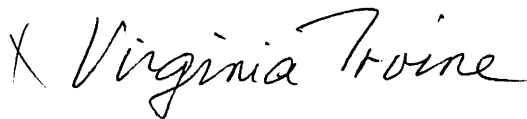
For the year ending 31 August 2025 the charitable company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared and delivered in accordance with the provisions applicable to companies subject to the small companies regime.

On behalf of the board

A handwritten signature in black ink that reads "X Virginia Irvine". The signature is written in a cursive style with a large 'X' at the beginning.

Mrs Virginia Irvine

Trustee

4 May 2026

The notes on pages 11 to 16 form part of these financial statements.

**Advocacy For Neuroacanthocytosis Patients**  
**Notes to the Financial Statements**  
**For The Year Ended 31 August 2025**

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**1. General Information**

Advocacy For Neuroacanthocytosis Patients is a company limited by guarantee, incorporated in England & Wales, registered number 07000073 and registered charity number 1133182. The registered office is .

**2. Accounting Policies**

**2.1. Basis of Preparation of Financial Statements**

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)", Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Companies Act 2006.

The charitable company is a Public Benefit Entity as defined by FRS 102.

**2.2. Fund Accounting**

Designated Funds are held in anticipation of requests for financial support of active research projects approved by the Board. The conditions of any grant allowed for an unconditional termination, however, the board feels a moral obligation after such grants have begun.

At 31 August 2025, there were no active research grants provided for as Designated Funds.

**2.3. Incoming Resources**

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.

**2.4. Resources Expended**

**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.

The company makes quarterly payments against the expenses invoices of grant recipients. £8,147 was paid to grant and symposium recipients during the year by the Advocacy of Neuroacanthocytosis Patients.

**2.5. Cash and Cash Equivalents**

Cash and cash equivalents are basic financial assets and include cash in hand and deposits held at call with banks, other short-term highly liquid investments that mature in no more than three months from the date of acquisition and are readily convertible to a known amount of cash with insignificant risk of change in value, and bank overdrafts.

**2.6. Foreign Currencies**

Monetary assets and liabilities in foreign currencies are translated into sterling at the rates of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate ruling on the date of the transaction. Exchange differences are taken into account in arriving at the operating surplus.

**Advocacy For Neuroacanthocytosis Patients**  
**Notes to the Financial Statements (continued)**  
**For The Year Ended 31 August 2025**

**2.7. Taxation**

The charity is exempt from tax as all its income is charitable and applied for charitable purposes.

**3. Income from Donations and Legacies**

	<b>2025</b>	<b>2024</b>
	<b>Unrestricted</b>	<b>Unrestricted</b>
	<b>funds</b>	<b>funds</b>
	<b>£</b>	<b>£</b>
Donations and gifts	65,398	45,207

**4. Investment Income**

	<b>Unrestricted</b>	<b>Restricted</b>	<b>2025</b>
	<b>funds</b>	<b>funds</b>	<b>Total</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Interest from investments	3,000	17	3,017
Dividends from investments	-	2,251	2,251
	<u>3,000</u>	<u>2,268</u>	<u>5,268</u>

	<b>Unrestricted</b>	<b>Restricted</b>	<b>2024</b>
	<b>funds</b>	<b>funds</b>	<b>Total</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Interest from investments	842	1,924	2,766
Dividends from investments	-	2,271	2,271
	<u>842</u>	<u>4,195</u>	<u>5,037</u>

**5. Analysis of Expenditure**

			<b>2025</b>
	<b>Activities</b>	<b>Grant</b>	
	<b>undertaken</b>	<b>funding of</b>	
	<b>directly</b>	<b>activities</b>	<b>Support costs</b>
	<b>£</b>	<b>(see note 6)</b>	<b>(see note 7)</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Other Resources Expended	1,008	-	38,120
Research Grants and Symposium	-	8,147	-
	<u>1,008</u>	<u>8,147</u>	<u>38,120</u>
			<u>47,275</u>

**Advocacy For Neuroacanthocytosis Patients**  
**Notes to the Financial Statements (continued)**  
**For The Year Ended 31 August 2025**

				2024
	Activities undertaken directly	Grant funding of activities (see note 6)	Support costs (see note 7)	Total
	£	£	£	£
Other Resources Expended	(110)	5,000	38,118	43,008
Research Grants and Symposium	-	9,000	-	9,000
	<u>(110)</u>	<u>14,000</u>	<u>38,118</u>	<u>52,008</u>

**6. Grants Payable**

				2025
	Grants to Institutions	Grants to Individuals	Support costs	Total
	£	£	£	£
Other Resources Expended	-	-	-	-
Research Grants and Symposium	8,147	-	8,147	16,294
	<u>8,147</u>	<u>-</u>	<u>8,147</u>	<u>16,294</u>

				2024
	Grants to Institutions	Grants to Individuals	Support costs	Total
	£	£	£	£
Other Resources Expended	-	5,000	-	5,000
Research Grants and Symposium	9,000	-	9,000	18,000
	<u>9,000</u>	<u>5,000</u>	<u>9,000</u>	<u>23,000</u>

Grants paid to institutions, included above, are as follows:

	2025	2024
	£	£
Lucia D Franceschi - Verona Grant	-	9,000
Universita de Verona	8,147	-
	<u>8,147</u>	<u>9,000</u>

**Advocacy For Neuroacanthocytosis Patients**  
**Notes to the Financial Statements (continued)**  
**For The Year Ended 31 August 2025**

**7. Support Costs**

	<b>2025</b>
	<b>Other Resources Expended</b>
	<b>£</b>
Employee costs	35,863
General administration	2,257
	<u>38,120</u>
	<b>2024</b>
	<b>Other Resources Expended</b>
	<b>£</b>
Employee costs	35,863
General administration	2,255
	<u>38,118</u>

**8. Staff Costs**

Staff costs were as follows:

	<b>2025</b>	<b>2024</b>
	<b>£</b>	<b>£</b>
Wages and salaries	<u>35,863</u>	<u>35,863</u>

No employees received employee benefits (excluding employer pension costs) for the reporting period of more than £60,000.

**9. Average Number of Employees**

Average number of employees during the year was: 1 (2024: 1)

**10. Debtors**

	<b>2025</b>	<b>2024</b>
	<b>£</b>	<b>£</b>
Due within one year		
Other debtors	<u>266</u>	<u>227</u>



**Advocacy For Neuroacanthocytosis Patients**  
**Notes to the Financial Statements (continued)**  
**For The Year Ended 31 August 2025**

**11. Current Asset Investments**

	2025	2024
	£	£
Listed investments	195,287	186,321

**12. Creditors: Amounts Falling Due Within One Year**

	2025	2024
	£	£
Other creditors	2,472	2,950

**13. Movement in Funds**

	As at 1 September 2024	Income	Expenditure	As at 31 August 2025
	£	£	£	£
<b>Unrestricted funds</b>				
General:				
General unrestricted fund	81,576	68,398	(46,576)	103,398
<b>Restricted funds</b>				
Harvard Donation	649	-	2	651
Glenn Irvine Prize Fund	117,700	2,268	6,697	126,665
Jeans for Genes	3,500	-	-	3,500
<b>Total restricted funds</b>	121,849	2,268	6,699	130,816
<b>Total funds</b>	203,425	70,666	(39,877)	234,214

	As at 1 September 2023	Income	Expenditure	As at 31 August 2024
	£	£	£	£
<b>Unrestricted funds</b>				
General:				
General unrestricted fund	81,863	46,049	(46,336)	81,576
<b>Restricted funds</b>				
Harvard Donation	651	-	(2)	649

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**Advocacy For Neuroacanthocytosis Patients**  
**Notes to the Financial Statements (continued)**  
**For The Year Ended 31 August 2025**

Glenn Irvine Prize Fund	111,333	4,195	2,172	117,700
Jeans for Genes	3,500	-	-	3,500
<b>Total restricted funds</b>	<b>115,484</b>	<b>4,195</b>	<b>2,170</b>	<b>121,849</b>
<b>Total funds</b>	<b>197,347</b>	<b>50,244</b>	<b>(44,166)</b>	<b>203,425</b>

**14. Transactions with Trustees**

None of the trustees received any remuneration or any other benefits from an employment with the charity or a related entity during the current or previous year.

During the year the expenses reimbursed to the trustees or paid directly to third parties were as follows:

	<b>2025</b>	<b>2024</b>
	<b>£</b>	<b>£</b>
Travel	392	-

Number of trustees reimbursed for expenses during the year was 1 (2024: 0)

**15. Related Party Disclosures**

There have been no related party transactions in the reporting period that require disclosure, except for those disclosed in the Transactions with Trustees note.